HEALTH SERVICES AND DELIVERY RESEARCH

VOLUME 4 ISSUE 8 FEBRUARY 2016
ISSN 2050-4349

Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem)

Frances Bunn, Anne-Marie Burn, Claire Goodman, Louise Robinson, Greta Rait, Sam Norton, Holly Bennett, Marie Poole, Johan Schoeman and Carol Brayne

DOI 10.3310/hsdr04080

National Institute for Health Research

Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem)

Frances Bunn,[1]* Anne-Marie Burn,[1] Claire Goodman,[1] Louise Robinson,[2] Greta Rait,[3] Sam Norton,[4] Holly Bennett,[5] Marie Poole,[2] Johan Schoeman[6] and Carol Brayne[5]

[1]Centre for Research in Primary and Community Care, University of Hertfordshire, Hatfield, UK
[2]Institute for Health and Society, Newcastle University, Newcastle upon Tyne, UK
[3]PRIMENT Clinical Trials Unit, Research Department of Primary Care and Population Health, University College London Medical School, London, UK
[4]Department of Psychology, Institute of Psychiatry, King's College London, London, UK
[5]Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK
[6]East London Foundation Trust, London, UK

*Corresponding author

Declared competing interests of authors: Professor Goodman reports grants from the National Institute for Health Research (NIHR) during the course of the study. Dr Norton reports grants from the NIHR Health Services and Delivery Research programme during the course of the study and grants from the NIHR Research for Patient Benefit programme and the Multiple Sclerosis Society, outside the submitted work.

Published February 2016
DOI: 10.3310/hsdr04080

This report should be referenced as follows:

Bunn F, Burn A-M, Goodman C, Robinson L, Rait G, Norton S, *et al*. Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem). *Health Serv Deliv Res* 2016;**4**(8).

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nihredit@southampton.ac.uk

The full HS&DR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the *Health Services and Delivery Research* journal

Reports are published in *Health Services and Delivery Research* (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme

The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: http://www.nets.nihr.ac.uk/programmes/hsdr

This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 11/1017/07. The contractual start date was in September 2012. The final report began editorial review in June 2015 and was accepted for publication in October 2015. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

Abstract

Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem)

Frances Bunn,[1]* Anne-Marie Burn,[1] Claire Goodman,[1] Louise Robinson,[2] Greta Rait,[3] Sam Norton,[4] Holly Bennett,[5] Marie Poole,[2] Johan Schoeman[6] and Carol Brayne[5]

[1]Centre for Research in Primary and Community Care, University of Hertfordshire, Hatfield, UK
[2]Institute for Health and Society, Newcastle University, Newcastle upon Tyne, UK
[3]PRIMENT Clinical Trials Unit, Research Department of Primary Care and Population Health, University College London Medical School, London, UK
[4]Department of Psychology, Institute of Psychiatry, King's College London, London, UK
[5]Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK
[6]East London Foundation Trust, London, UK

*Corresponding author f.bunn@herts.ac.uk

Background: Among people living with dementia (PLWD) there is a high prevalence of comorbid medical conditions but little is known about the effects of comorbidity on processes and quality of care and patient needs or how services are adapting to address the particular needs of this population.

Objectives: To explore the impact of dementia on access to non-dementia services and identify ways of improving the integration of services for this population.

Design: We undertook a scoping review, cross-sectional analysis of a population cohort database, interviews with PLWD and comorbidity and their family carers and focus groups or interviews with health-care professionals (HCPs). We focused specifically on three conditions: diabetes, stroke and vision impairment (VI). The analysis was informed by theories of continuity of care and access to care.

Participants: The study included 28 community-dwelling PLWD with one of our target comorbidities, 33 family carers and 56 HCPs specialising in diabetes, stroke, VI or primary care.

Results: The scoping review ($n = 76$ studies or reports) found a lack of continuity in health-care systems for PLWD and comorbidity, with little integration or communication between different teams and specialities. PLWD had poorer access to services than those without dementia. Analysis of a population cohort database found that 17% of PLWD had diabetes, 18% had had a stroke and 17% had some form of VI. There has been an increase in the use of unpaid care for PLWD and comorbidity over the last decade. Our qualitative data supported the findings of the scoping review: communication was often poor, with an absence of a standardised approach to sharing information about a person's dementia and how it might affect the management of other conditions. Although HCPs acknowledged the vital role that family carers play in managing health-care conditions of PLWD and facilitating continuity and access to care, this recognition did not translate into their routine involvement in appointments or decision-making about their family member. Although we found examples of good practice, these tended to be about the behaviour of individual practitioners rather than system-based approaches; current systems may unintentionally block access to care for PLWD. Pathways and guidelines for our three target conditions do not address the possibility of a dementia diagnosis or provide decision-making support for practitioners trying to weigh up the risks and benefits of treatment for PLWD.

Conclusions: Significant numbers of PLWD have comorbid conditions such as stroke, diabetes and VI. The presence of dementia complicates the delivery of health and social care and magnifies the difficulties that people with long-term conditions experience. Key elements of good care for PLWD and comorbidity include having the PLWD and family carer at the centre, flexibility around processes and good communication which ensures that all services are aware when someone has a diagnosis of dementia. The impact of a diagnosis of dementia on pre-existing conditions should be incorporated into guidelines and care planning. Future work needs to focus on the development and evaluation of interventions to improve continuity of care and access to services for PLWD with comorbidity.

Funding: The National Institute for Health Research Health Services and Delivery Research programme.

Contents

List of tables

List of figures

List of boxes

List of abbreviations

AIS	acute ischaemic stroke
AMD	age-related macular degeneration
CFAS	Cognitive Function and Ageing Studies
CGA	comprehensive geriatric assessment
CI	confidence interval
DeNDRoN	Clinical Research Network Dementias and neurodegeneration
DSM-IV	*Diagnostic and Statistical Manual of Mental Disorders*-Fourth Edition
GMS-AGECAT	Geriatric Mental State – Automated Geriatric Examination for Computer Assisted Taxonomy
GP	general practitioner
HCP	health-care professional
IPU	integrated practice unit
IV tPA	intravenous tissue plasminogen activator
MCI	mild cognitive impairment
MMSE	Mini Mental State Examination
MRC	Medical Research Council
NETSCC	NIHR Evaluation, Trials and Studies Coordinating Centre
NIHR	National Institute for Health Research
PLWD	person/people living with dementia
QOF	Quality Outcomes Framework
RCT	randomised controlled trial
VI	vision impairment

Plain English summary

In the UK people living with dementia (PLWD) have an average of 4.6 long-term medical conditions in addition to their dementia. Despite this, health-care services are generally organised around single conditions rather than caring for the person as a whole. The aim of this study was to explore how having dementia alongside diabetes, stroke or vision impairment affects access to care and to identify ways in which services might be improved for this group.

We undertook (1) a review of the literature, (2) a statistical analysis of differences in service use between people with and people without dementia, (3) interviews and group discussions with 28 PLWD, 33 family carers and 56 health-care professionals (HCPs) and (4) a conference in which HCPs, members of the public and representatives from the voluntary sector generated priorities for research and practice.

We found that PLWD may have poorer access to health services than those without dementia. Systems are not designed to involve family carers in decision-making and there is a lack of guidance for HCPs when they are making decisions about care, for example when weighing up the risks and benefits of treatment.

Key elements of good care for PLWD and other medical conditions include having the PLWD and family carer at the centre, flexibility around processes and good communication, which ensures that all services are aware when someone has a diagnosis of dementia. Guidance for HCPs needs to take into account the impact of a diagnosis of dementia on pre-existing conditions such as diabetes.

Scientific summary

Background

Dementia is a significant public health problem with far-reaching health, social and economic impacts and the prevalence of dementia in the UK is set to rise significantly. Evidence suggests that among people with dementia there is a high prevalence of comorbid medical conditions and complaints, but little is known about the effects of comorbidity on processes and quality of care and patient needs or how services are adapting to address the particular needs of this population. Dementia is often viewed as an isolated condition with little understanding of how other complex health needs might impact on patient and carer experiences or service use and provision.

Aims

The overall aims of this study were to explore the impact of comorbidities for a person living with dementia (PLWD) on access to non-dementia services and identify ways of improving integration of services for this population. We focused specifically on three conditions: diabetes, stroke and vision impairment (VI).

Methods

We used a mixed-methods approach informed by theories of continuity and access to care. This included:

(a) a scoping review of relevant literature to map what is currently known about comorbidity and dementia
(b) a cross-sectional analysis of the Cognitive Function and Ageing Studies (CFAS) population cohort database to explore health and social service use in people with a diagnosis of dementia and a comorbid medication condition
(c) a qualitative study exploring the views and experiences of people with dementia and comorbidity, their family carers and health-care professionals (HCPs)
(d) consensus methods to help develop ideas/recommendations for practice.

Results

Scoping review

We included 76 studies or reports that addressed issues around dementia and comorbidity, focusing on diabetes, stroke and VI. There was evidence of a lack of continuity in health-care systems and structures for people with dementia and comorbidity, with little integration or communication between different teams and specialities. Thirty-one studies reported prevalence data, either for one of our three target comorbidities in people with dementia or for dementia in people with stroke, diabetes or VI. Although heterogeneity in the populations and differences in the way that conditions were ascertained make comparisons across studies difficult, the data do suggest that the rate of diabetes in people with dementia may be between 13% and 20% and of stroke may be between 16% and 29%. Of the 11 studies that compared access to treatment or receipt of services in groups with and without dementia, 10 found some evidence that people with dementia were less likely to receive the same quality of care or access to services than those without dementia.

Cognitive Function and Ageing Studies

The CFAS I and CFAS II are longitudinal multicentre population studies conducted in the UK. In CFAS II the prevalence of dementia, in those living in the community was 5.3%. Of these people with dementia, 17% had diabetes, 18% had had a stroke and 17% had a VI. The aim of the CFAS II-only analysis was to see whether or not there was any difference in service use between those with dementia and a target health condition and those with either dementia alone or the health condition alone. Unpaid care was the most commonly used service in CFAS II. When comparing unpaid care use by those with dementia and a target health condition with unpaid care use by those with only the health condition, in every case unpaid care was used considerably more by those with dementia and a target health condition. As well as unpaid care, those with dementia and a target health condition also used a home care assistant, day centre and care worker more than those with the health condition alone. When comparing hospital service use by those with dementia and a target health condition with hospital service use by those with dementia alone, inpatient services were used more by those with dementia and a target health condition.

The comparison analysis between CFAS I and CFAS II looked at whether or not there were any differences in service use over the last decade. The main difference seen was in hospital service use, which increased dramatically over this time because of the increase in use of day patient and outpatient services. There was also a marked increase in the use of unpaid care by those with dementia and either diabetes or VI. However, the number of people with dementia and a target health condition was not large enough in the CFAS I 10-year follow-up wave to test this formally.

Interviews and focus groups

We conducted interviews with 28 people with dementia and 33 family carers and focus groups or interviews with 56 HCPs specialising in primary care or one of our three target comorbidities (diabetes, stroke or VI). Of the PLWD, > 50% had diabetes, 45% had some form of VI and 28% had had a stroke. Our two overarching themes were:

1. negotiating continuity, including relationship, management and informational continuity
2. negotiating access to care, including appropriateness, comprehensiveness and equity.

Negotiating continuity

The personal characteristics of HCPs and the communication of information in a timely and sensitive manner appeared to be key to developing a trusting relationship with a HCP. The absence of a standardised approach to sharing information about a person's dementia and how it might affect the management of other conditions was a recurrent issue. This had implications for how appointments were planned and organised and how carers were involved. HCPs involved in delivering care for people with our target comorbidities commented that they were often unaware that someone had dementia. Instead, informational continuity was often provided by family carers attending appointments and transferring information between specialities. We found little evidence of services developing processes to support informational continuity or using tools such as 'This is me' [see http://alzheimers.org.uk/thisisme (accessed 7 January 2016)] to support continuity of information.

Family carers often played a significant role in managing and co-ordinating the care of their relative; this sometimes involved having to learn new skills such as checking blood sugar or giving insulin injections. The transition from self-management to dependency could be gradual or sudden and was often unpredictable or understood only in hindsight. HCPs who we spoke to acknowledged the vital role that family carers play but, from carers' accounts, it was clear that this recognition did not translate into routine involvement or engagement of family carers in appointments or decision-making about their family member.

Negotiating access

We found many examples in which systems or environments had unintentionally blocked access to care for PLWD, for example appointments made over the telephone, long waits in busy clinic environments, tests that were not appropriate for PLWD, new technology introduced without proper explanation, lack of involvement of family carers and a failure to engage with social care as the main source of support for PLWD at home. Despite evidence of awareness among staff that PLWD could need more time for consultations, clinic structures and pressures of patient numbers meant that there was generally little capacity to achieve this for PLWD. Pathways and guidelines for our three target conditions did not address the possibility of a dementia diagnosis or provide decision-making support for practitioners trying to weigh up the risks and benefits of treatment for PLWD. Moreover, many HCPs in our study reported that they felt underprepared to care for PLWD. There were examples of good practice but this tended to be about the behaviour of individual practitioners rather than system-based approaches. Decisions about treatment for PLWD were made in the context of clinicians' attitudes and perceptions of dementia, and concerns about polypharmacy, consent, multimorbidity and concordance.

Conclusions

Significant numbers of PLWD have comorbid conditions such as stroke, diabetes and VI, and many of them have multimorbidities. The presence of dementia complicates the delivery of health care and magnifies the known difficulties that people with long-term conditions experience when navigating health and social care. The situation is further complicated as some people will develop comorbidity in the presence of already diagnosed dementia and others will develop dementia subsequent to a comorbidity such as diabetes, stroke or VI.

The delivery of high-quality care to patients with dementia demands a particularly high standard of care across multiple domains, including communication, multidisciplinary care, clinical decision-making and engagement with families and carers. Effective care for older patients with dementia will help set a standard of care of universal relevance to vulnerable adults. Good care for PLWD and comorbidity may vary according to the type of condition(s) that they have. However, key elements include having the PLWD and the family carer at the centre, flexibility around processes, good communication between services, ensuring that all services are aware when someone has a diagnosis of dementia, taking into account the impact of a diagnosis of dementia on pre-existing conditions and incorporating this into guidelines and care planning.

There is already a great deal of descriptive work on the experiences of PLWD and their family carers. This study adds to that by providing information about the prevalence of comorbidities, service use among PLWD and comorbidity and how having dementia impacts on the management of comorbid health conditions in PLWD. In the following sections we discuss the implications for practice and provide a number of recommendations for research. We suggest that future work needs to focus on the development and evaluation of interventions rather than on further descriptive studies. PLWD should be included in the debate about the management of comorbidities in older populations and there needs to be greater consideration given to including them in studies that focus on age-related health-care issues.

Implications for practice

- The evidence suggests that the use of tools such as the triangle of care model may be helpful in ensuring that the input of family carers is properly recognised. This should include the identification of family carers, appropriate training in carer engagement for staff, and policy and practice protocols regarding confidentiality and information sharing.
- Our study suggests that systems for booking appointments need to be made more 'dementia friendly', for example, sending reminders, including nominated family carers in all correspondence (this may not be the primary carer if the primary carer is a spouse with memory problems) and not booking appointments by telephone.

- The evidence suggests that staff at all levels, including more senior staff, need appropriate training on dementia. Some training may need to be tailored to specific conditions, for example identifying the best strategies for the rehabilitation of PLWD who have had a stroke.
- Professional bodies for HCPs may need to consider how the current provision of dementia training on undergraduate programmes can be improved.
- HCPs in specialist areas are often unaware that someone has dementia. Our evidence suggests that a diagnosis of dementia should be flagged up on medical/electronic records. This should include systems for automatic updates of a dementia diagnosis to be transferred to health-care services that a PLWD is already attending.
- PLWD who live alone or who do not have family support may be particularly disadvantaged and may need additional help to navigate systems and access care.
- PLWD are likely to benefit from longer appointments, in both primary and secondary care.
- PLWD may need a suitably trained staff member to help them navigate clinic environments; they may also benefit from assessments carried out by specialists in their own home or at their local general practice surgery.
- HCPs caring for people with cognitive impairment and long-term conditions, such as diabetes, need to regularly assess patients' ability to self-manage and identify when they may need additional support.
- Evidence suggests that there is a need for better integration of physical and mental health-care systems, that is, old-age psychiatry teams and geriatric teams working together and community-based geriatric teams having specialist mental health care as an integral part of the team.
- Our study suggests that, for PLWD and diabetes, who need support from health and social care, there is a need to link medication and monitoring of diabetes with the provision of meals.
- The evidence suggests that PLWD and diabetes may not be getting regular eye and foot checks.

Recommendations for future research

Potential areas for future research identified by the study include the following:

- What makes a 'good' dementia Quality and Outcomes Framework, for example what components should be routinely included and should they include physical health checks?
- What is the impact of providing PLWD and their family carers with support, either from a professional or from a trained lay person, to help navigate health-care systems?
- What are the impacts on PLWD, family carers and other HCPs of specialist dementia nurses, such as Admiral Nurses, working in hospital and community settings?
- Is a collaborative care approach, with a case manager to provide integrated physical and psychological care, an effective approach to the provision of dementia care for PLWD and comorbidity and which populations of PLWD are most likely to benefit from collaborative care and at what stage?
- What is the impact of dementia case finding for older people with stroke, diabetes and VI, for example the use of case finding on admission to hospital or at the first clinic appointment?
- What is the impact of expanding the 'This is me' document to include health-related information?
- How can patients, carers and HCPs be encouraged to use the 'This is me' document?
- What interventions can be used to improve medication management in PLWD; for example, what is the impact of pharmacists carrying out short cognitive screening of older patients with multiple medications?
- Diabetes – how can HCPs caring for people with long-term conditions and dementia be helped to recognise when a person is no longer able to self-manage?
- Diabetes – what is the impact of self-management interventions for diabetes that involve family carers of adults with diabetes and cognitive impairment?
- Diabetes – what is the impact of personalised glycaemic targets for PLWD on outcomes such as hypoglycaemic attacks, hospital admissions and falls?
- Stroke – what are the most effective and cost-effective approaches to stroke rehabilitation for people with dementia?
- VI – how can tests for VI be made appropriate or adapted for PLWD?

- VI – is it possible to fast track PLWD for treatment such as surgery for cataracts and, if so, what are the impacts of this?
- VI – how can ophthalmology clinics and other health-care environments be made to be more dementia friendly so that they are suitable for people with VI or sight loss as well as dementias?

Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.

Chapter 1 Background

Introduction

Dementia is primarily a condition of old age and as such many people with dementia will have other long-term health conditions.[1,2] As the population ages and the proportion of people with both dementia and multimorbidity increases, the delivery of health care becomes increasingly complex and challenging.[3] Despite this, health-care systems and research often treat dementia as an isolated condition with little understanding of how other complex health needs might impact on patient and carer experiences or service use and provision.[4] There is a need to consider what kind of system-based support can enable different health-care professionals (HCPs), patients and their carers to navigate the multiple systems of care that they might encounter; to explore decision-making processes; and to understand barriers to and facilitators of the development of an integrated approach to care across services for people living with dementia (PLWD).

Dementia and comorbidity

Dementia affects one in 20 people aged > 65 years and one in five people aged > 80 years.[5] Over 800,000 people in the UK have dementia,[6] with the most common form being Alzheimer's disease.[7] This number is forecast to increase by 40% over the next 12 years.[8] Although there are significant differences in the physical and cognitive effects of the different types of dementia, all are progressive, involve increasing physical and mental deterioration and lead to PLWD becoming increasingly dependent. The prevalence of dementia in patients aged > 65 years in general hospitals is high and it is estimated that at any one time one-quarter of acute hospital beds are occupied by PLWD.[9]

There are different conceptualisations of comorbidity but they are based on the core concept of more than one distinct condition in an individual.[10] The existence of several long-term conditions in one individual is common in PLWD[1,2,11] and a study in the UK found that, on average, people with dementia had 4.6 chronic illnesses in addition to their dementia.[4] In addition, delirium, infections, falls, urinary and faecal incontinence and constipation occur more frequently in PLWD.[1,12]

Common health conditions in PLWD include diabetes, vascular or heart disease, hypertension, chronic obstructive pulmonary disease, musculoskeletal disorders and chronic cardiac failure.[1,13,14] There is increasing evidence to support an association between Alzheimer's disease and cardiovascular risk factors such as hypertension and hypercholesterolaemia.[15–17] It has been argued that in older age groups Alzheimer's disease should be considered as a diffuse clinical syndrome representing the gradual accumulation of multiple pathologies rather than as a discrete neuropathological entity.[15]

Health-care delivery for people with dementia and comorbidity

Comorbidity among people with dementia presents particular challenges for primary and secondary care. Certain comorbid medical conditions may exacerbate the progression of dementia. For example, there is evidence that cognitive decline may be accelerated in older people with type 2 diabetes.[18,19] Moreover, the presence of dementia may adversely affect the clinical care of other conditions and undermine a patient's ability to self-manage chronic conditions and engage in health maintenance activities.[20,21] The presence of dementia can be a key factor in how different specialist and emergency services are used and in decision-making about transfer to long-term care (nursing homes).

Despite this, most research has been concerned with the effect of multimorbidity on physical functioning and its measurement, with little research investigating the effect on processes of care or what constitutes 'best care' for PLWD.[22] In addition, little is known about patients' perspectives. A review of 126 qualitative research papers on patients' experiences of the diagnosis and treatment of dementia[23] found very little evidence relating to the experiences of people diagnosed with dementia who have an accompanying comorbid condition. In fact, this group are often actively excluded from research even though it is likely that a diagnosis of dementia may affect their ability to self-manage other conditions. There is a lack of research on patients' views on the ways in which multiple conditions affect their health, well-being and clinical care.[10]

Rationale for the research

It has been consistently highlighted that NHS professionals who do not work in mental health have very little understanding of the needs and experiences of PLWD and that the care needs of PLWD are frequently not being met.[24–26] Suboptimal systems and insufficient guidance for generalist and specialist services that encounter patients with dementia and other comorbid conditions result in the duplication of services, delays in the identification of problems and ultimately patients being admitted to hospital or transferred to long-term care earlier than is necessary.[9,27]

Improving the organisation and delivery of services for PLWD remains a key government target.[25,28] A report from the Ministerial Advisory Group on Dementia Research Subgroup 1[29] identified several priority topics for dementia research, one of which was a need for more research addressing comorbidities, especially in relation to vascular disease, and a need to improve the physical health of patients with dementia. In addition, there is a growing recognition that current health-care services may not be designed to meet the needs of older people with complex health needs such as multimorbidity.[3,4]

To date, research has tended to focus on the experience of living with dementia as a single disease. Moreover, although there is a growing awareness of the needs of patients with multimorbidity and frailty,[30] there is little research on the specific needs of PLWD. The aim of this research was to add to our understanding of how having dementia impacts on the management of other health conditions. It summarises current evidence in this field, provides valuable information about how dementia impacts on the management of comorbid health conditions and provides suggestions for how services should be organised and delivered to improve quality of care for people with complex health conditions who are diagnosed with dementia.

Aims and objectives

The overall aims of the study were to:

1. explore the impact of comorbidities for a PLWD on access to non-dementia services
2. identify ways to improve the integration of services for this population and reduce fragmentation and the inappropriate use of care.

The research objectives were to map what is already known about comorbidity and dementia, identify how the presence of dementia impacts on access to health care and service delivery for comorbid conditions, identify barriers to and facilitators of service delivery for people with dementia and comorbidities and identify models of service delivery that are best suited to meet the needs of people with dementia who have other complex health-care needs. The research questions were:

1. What is best practice/effective care for service delivery for people with dementia and a comorbid condition [i.e. diabetes, stroke and vision impairment (VI)]?
2. How does the presence of one or more comorbidity impact on access to health care and service delivery for people with dementia, their carers and health and social care professionals?
3. What are the barriers to and facilitators of service delivery for people with dementia and comorbidities?
4. How can current services adapt to meet the needs of people with dementia who have other complex health-care needs?

Structure of the report

Chapter 2 describes the conceptual approach adopted and the framework used to structure the qualitative analysis and *Chapter 3* details the methods of each phase of the study. The findings of the scoping review are presented in *Chapter 4*, the analysis of the Cognitive Function and Ageing Studies (CFAS) data is presented in *Chapter 5*, the interviews and focus groups are presented in *Chapter 6* and the consensus conference is described in *Chapter 7*. Finally, *Chapter 8* summarises the study findings and looks at their implications, in particular how current services can adapt to meet the needs of PLWD who have other complex health needs.

Chapter 2 Conceptual framework and approach

We used a mixed-method approach that was informed by theories about continuity of care[31–33] and access to care.[34]

Continuity of care

In its simplest terms continuity may be considered as the degree to which a series of discrete health-care events is experienced as coherent and connected and consistent with the patient's needs and personal context.[31] There is evidence that increased continuity is associated with improved outcomes and satisfaction.[35,36] Although continuity may be important to all health service users, it is thought to be particularly important for those with complex health needs such as dementia, long-term conditions, multimorbidity and frailty.[37,38]

Dementia is a long-term condition characterised by progressive deterioration and dependency. Navigating the different systems of care is particularly difficult for this population, not least because they receive advice and support from health and social care and increasingly third-sector providers.[39] Previous research on continuity has identified a need to prioritise the needs of vulnerable people who are unable to negotiate their own continuity as they wish.[40] Processes of care may be further complicated for PLWD who have other comorbid health conditions. Increasing specialisation of care for long-term conditions means that they are likely to see a variety of different HCPs in a number of different places.[3] This leads to further fragmentation of care and reduced continuity.[41]

Continuity of care is a complex multidimensional concept that can refer to relationships between patients and practitioners, co-ordination across services, information transfer and co-ordination of care over time, and the coherent delivery of services for people with long-term conditions.[31] Theories about continuity of care provide an appropriate framework for exploring the health-care experiences of PLWD and ensure that activities that support coproduction of care are identified and considered. Older people with complex health needs value continuity and consistency of services, timely communication and follow-up between services, respectful delivery of services and HCPs who are familiar with their needs and can help them navigate multiple services.[42–44] Recent discourse around continuity has moved towards a partnership paradigm in which continuity is recognised to be coconstructed by patients, families and professionals, all of whom have an active part to play in its accomplishment.[33,45] In this model 'professionals do not deliver continuity to service users but work with them and their carers/families to assess needs and preferences and facilitate contact and continuity' (p. 597).[46]

Freeman and colleagues[40] have identified three main aspects of continuity: relationship continuity, management continuity and informational continuity. These categories are clearly not mutually exclusive and key concepts are common to all of them. The main aspects of each type of continuity are outlined in the following sections.

Relationship continuity

Relationship continuity refers to the continuous therapeutic relationship with one or more health professionals over time.[40] The relationship might be established with a single provider or with a team.[31] Relationship continuity with a trusted provider is seen to be a key attribute of high-performing primary care and is known to be important to patients and carers.[41,47,48] Moreover, good relationship continuity facilitates management and informational continuity.[41] Despite this, it is an aspect of care that has been relatively neglected in the literature.[47] Implied in the concept of relationship continuity is the idea that the health-care provider involved knows the patient as a person first.[47] This has particular importance for people with dementia where a focus on person-centred care that emphasises a good knowledge of the person's priorities, preferences and previous history is the bedrock of good dementia care.[49] Individuals'

families are acknowledged to be a vital source of support for people with dementia, and care for people with dementia has evolved to recognise that relationships often involve triads including service users, their family carers and health and social care professionals.[50,51]

Management continuity

Management continuity refers to processes involved in co-ordinating, integrating and personalising care, involving communicating both facts and judgements across team, institutional and professional boundaries and between professionals and patients. In the USA the National Quality Forum[52] defines co-ordination as 'a function that ensures that the patient's needs and preferences for health services and information sharing across people, function and sites are met over time'. Management continuity includes the personalisation of care. The idea that personalising care is linked to improving the delivery of health care is a core tenet of many policy documents in the UK.[53] This links with concepts about the importance of providing person-centred care for people with dementia, core components of which include valuing the person with dementia and those who care for him or her and treating people as individuals.[54,55]

Informational continuity

Informational continuity refers to record-keeping and the transfer of information, the timely availability of relevant information and patients' and their carers' understanding of their condition and treatment. Documented information tends to focus on the medical condition but this information is complemented by clinicians' knowledge of the patients' preferences, values and context, knowledge that accumulates over the course of a number of interactions with the patient.[31,41] However, the increasing complexity of care delivered by a variety of providers means that continuity can no longer rely on relationships with individual providers.[56] It has been argued, therefore, that as information continuity is conducive to automation and systematisation it could be the principal tool underpinning the co-ordination of care.[57]

Individuals' capacity to receive and understand information is a factor that influences continuity and concepts of informational continuity have been widened to include the recognition that people have different capacities for receiving information.[46] For PLWD, family carers may often be responsible for the transfer of information between different health providers, particularly as the dementia progresses. Despite this there is currently a lack of knowledge about the roles that family caregivers play in maintaining informational continuity.[57] People may live with dementia and other chronic conditions for a considerable time[58] and it may be necessary for informational continuity to be maintained over sustained periods of time.

Access to care

In addition to continuity, issues around access to health and social care for PLWD emerged as particularly important in our scoping review of the literature (see *Chapter 4*).[59] This included issues around access to services, quality of care and appropriateness or comprehensiveness of care for PLWD. These have all been recognised as core dimensions of good care.[60] Commentators have argued that continuity should not be promoted over access but that both should be seen as equally important.[37,61]

Access is concerned with the processes of gaining entry to the health-care system. This may be extended to include the processes of gaining entry to higher levels of care for those already admitted to lower levels of care, sometimes referred to as 'in-system' access.[62] The availability of services (having access) and utilisation of services (gaining access) are generally seen as key dimensions. Pechansky and Thomas[63] suggested that the concept of access described the 'degree of fit' between clients and the health system. They identified five relevant dimensions to the client–service interaction: acceptability, affordability, availability, physical accessibility and accommodation. In high-income countries such as the UK, access to care can concern the degree of comprehensiveness that can be offered by heath-care systems, the extent to which equity is achieved and the timeliness and outcomes of care.[64] The appropriateness of services and

their effectiveness at achieving the desired health outcomes are also considered to fall within the scope of conventional access models.[34]

There are a number of organisational, geographical and financial barriers to access to care. For example, there may be costs associated with travelling to appointments and payment for some services, such as social care or eye checks, may be a barrier to access. Organisational barriers might include long waiting times for services or appointments and a failure to design services around the needs of patients.[34] In addition, personal, social and cultural influences may facilitate or impede the uptake of services.[34] Access is dependent on a person recognising a need for services and seeking help.[34,65] In the same way that dementia impacts on an individual's ability to negotiate his or her own continuity of care, it may also impact on access to care.

Dixon-Woods and colleagues[66] argue that equity of access is often measured by the use of health services but they suggest that access should be understood using the concept of candidacy. Candidacy describes how eligibility for health care is jointly negotiated between individuals and health services. Individuals need to view themselves as legitimate candidates for particular services, navigate gatekeeping within a service and have their candidacy validated by HCPs.[66,67] However, PLWD may lack the agency required for candidacy and may be dependent on family members or HCPs to identify a need for services and negotiate access to care on their behalf.

Framework

We used the different dimensions of continuity of care and access to care as a framework to structure how we asked questions and organised the analysis about the impact of living with dementia and other conditions for patients, carers and health-care providers at different points of the disease trajectory; to identify how continuity and access may be enhanced for this vulnerable group; and to inform how we considered service delivery from health-care providers.[32,40]

The key aspects of the framework for this study were:

- continuity:
  - relationship continuity
  - management continuity
  - information continuity
- access to care:
  - appropriateness of care
  - comprehensiveness of care
  - candidacy
  - equity.

Summary

This chapter describes the conceptual framework that informed the original design of the study and provides a critique of the different components of continuity and access to care. It has highlighted what supports and inhibits access to health care and continuity of care with particular reference to the needs of PLWD and their family carers.

Chapter 3 Research plan and methods

Overview of the research plan

The research was undertaken in three phases (*Figure 1*).

Phase 1

To understand current knowledge on the range and type of comorbid disease among PLWD and the impact of comorbidity on experiences and service use we:

- scoped current evidence on the prevalence of comorbidities in PLWD, the experiences and attitudes of patients and carers and the systems and structures that exist for the care of PLWD and comorbid medical conditions
- undertook a cross-sectional analysis of a population cohort database to explore health and social service use in people with a diagnosis of dementia and a comorbid medication condition.

Phase 2

To understand current models of service delivery, the points in the disease trajectory that pose the greatest challenges for service providers and barriers to and facilitators of access and continuity of care we undertook:

- interviews with PLWD and a comorbid medical condition and their family carers
- focus groups and interviews with clinicians involved in the care of PLWD and a comorbid medical condition.

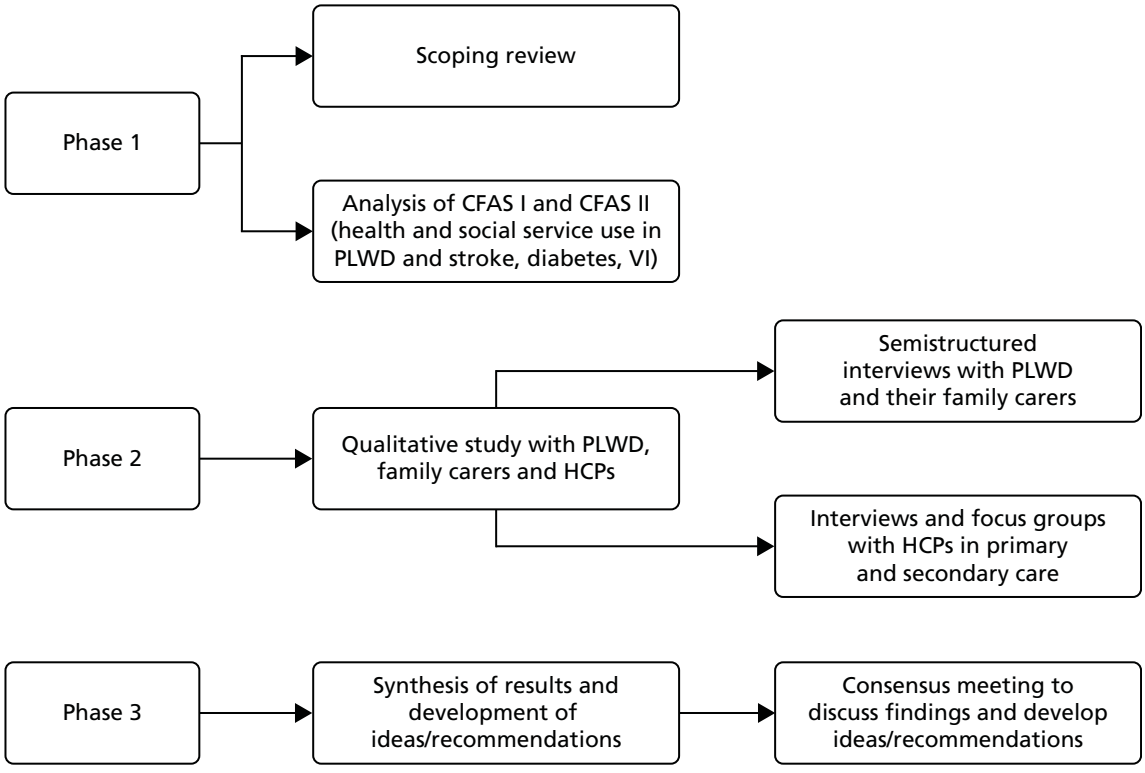

FIGURE 1 Diagrammatic summary of methods.

Phase 3

In the final phase of the study we brought together the findings from phases 1 and 2 to:

- map current models of care and how the presence of dementia with one or more comorbid condition is addressed by service providers
- highlight interventions that support continuity and equity of access to care that can be incorporated into current models of service delivery
- develop and refine ideas/recommendations about how services should engage with PLWD and their (family) carers.

We focused on three exemplar comorbid medical conditions, stroke, diabetes and VI, all of which generally involve some form of external clinical monitoring and require collaboration between primary and secondary care. Stroke and diabetes were chosen because they are common in older people[68,69] and are thought to exacerbate or influence the progression of dementia.[70] Moreover, management of these conditions, in particular self-management, is likely to be complicated by the presence of dementia.[21] VI is also prevalent in older people[71] and may exacerbate confusion.[72] In addition, the ability to cope with VI is reduced if a person also has dementia. Furthermore, although it is vital that eyesight is optimal in older people with dementia to maintain orientation and independence, there is a lack of uptake of services for this group, with few undergoing regular eye examinations.[73,74]

Phase 1: scoping review

The scoping review was guided by Arksey and O'Malley's[75] methodological framework,[76] which includes identifying the research question, searching for relevant studies, selecting studies, charting the data, and collating, and summarising and reporting the results. This approach allowed us to incorporate a range of study designs and address questions beyond those related to treatment efficacy. Although the scoping review has a number of similarities to a systematic review it does not typically involve quality assessment and findings are reported in a narrative format.[77,78] The inclusion criteria and methods for the review were prespecified in a protocol.[79]

Identifying the research question

Inclusion criteria

We included studies involving PLWD who had an additional comorbid health condition. Although we included all types of comorbidities there was a particular focus on our three exemplar comorbid medical conditions: diabetes, stroke and VI. We focused on community-dwelling participants and excluded studies in long-term care settings. We looked for studies relating to the prevalence of comorbidities in people with dementia or cognitive impairment; current systems, structures and other issues relating to service organisation and delivery; patient and carer experiences; and the experiences and attitudes of service providers. We included all study types including systematic reviews, randomised controlled trials (RCTs), controlled studies, observation studies and qualitative studies using any recognisable qualitative methodology. In addition, we included non-research items such as clinical guidelines. We excluded studies disseminated in languages other than English.

Searching for relevant studies

We searched for a representative range of material that provided an overview of current knowledge and that identified some key examples of developments in the organisation and delivery of care for people with dementia and comorbid conditions. We included published and unpublished literature with no date restrictions. Studies were identified by computerised searches of the Allied and Complementary Medicine Database (AMED), The Cochrane Library [including the Cochrane Central Register of Controlled Trials (CENTRAL), the Cochrane Database of Systematic Reviews, the Database of Abstracts of Reviews of Effects and the Health Technology Assessment database], the Cumulative Index to Nursing and Allied Health

Literature (CINAHL) (EBSCO*host*) (1980–2012), PubMed (1950–2012), NHS Evidence and Scopus (1966–2012). The electronic search strategy was developed by an experienced information scientist with input from the project team. An example of the search query for PubMed is given in *Appendix 1*. In addition, we employed extensive lateral search techniques such as checking reference lists, performing keyword searches in Google Scholar (Google Inc., Mountain View, CA, USA) and using the 'cited by' option in PubMed. We also contacted experts and those with an interest in dementia such as the Alzheimer's Society, the Thomas Pocklington Trust, the Royal National Institute for the Blind, Diabetes UK, the Stroke Association and the Dementia and Sight Loss Interest Group. Such lateral strategies have been shown to be particularly important for identifying non-randomised studies.[80] The original electronic database searches were conducted in September 2012, with the PubMed search updated in November 2013 and lateral searches updated in February 2015.

Selecting studies and charting the data

Electronic search results were downloaded into EndNote bibliographic software (X7; Thomson Reuters, CA, USA) and, when possible, duplicates deleted. Two authors (FB and AB) independently screened titles and abstracts identified by the electronic search and applied the selection criteria to identify potentially relevant papers. Data were extracted by one author using a standardised checklist and checked by a second. Any disagreements were resolved by consensus or by discussion with a third author (CG). When the results of a study were reported in more than one publication, we grouped the reports together and marked the publication with the most complete data as the primary reference; the other papers describing the same study were classified as associated papers. Data extracted included type of item (e.g. empirical study, review, guideline), aims/research questions, methods, study focus, participants, setting and relevant outcome data (e.g. rates of comorbidities, access to treatment, patient and carer views).

Reporting the results

Studies were grouped into the following categories: (1) prevalence, (2) quality of care, (3) views and experiences (patients, carers and HCPs) and (4) health service organisation and delivery. Data were primarily reported in a narrative format. For the data on the prevalence of diabetes and stroke, forest plots have been used to graphically display (1) the prevalence of dementia comorbid with each of the target conditions in studies in which the target condition was the index condition and (2) each target condition comorbid with dementia in studies in which dementia was the index condition. Because of heterogeneity in the study designs and the lack of availability of age- and sex-standardised prevalence rates in the manuscripts, pooled estimates were not calculated.

The results of the scoping review were presented to and discussed with stakeholders at the University of Hertfordshire AgeNet research group. This group attracts an audience of older people, voluntary sector representatives, staff from health and social care and academics.

Phase 1: secondary data analysis

Sample and procedure

Data from two longitudinal multicentre population-based studies in the UK – CFAS I and CFAS II – were analysed. A detailed description of the samples and methodology is provided on the CFAS website [see www.cfas.ac.uk (accessed 7 December 2015)].

The CFAS I cohort consists of a sample of 13,004 individuals aged ≥ 65 years recruited between 1991 and 1993. Participants were randomly sampled from Family Health Service Authority lists in Cambridgeshire, Gwynedd, Newcastle, Nottingham, Liverpool and Oxford. These areas were selected to provide good geographical spread across urban and rural locations. Baseline interviews included questions about sociodemographic characteristics, lifestyle, health, activities of daily living and cognition. For CFAS I, repeated follow-up interviews took place on several occasions, with attempts to interview the entire sample at 2 and 10 years. The presence of health conditions was ascertained at each interview, although

questions on service use were introduced for the whole sample during the 10-year follow-up interview. Data at 10 years were naturally available only for survivors who were aged ≥ 75 years ($n = 3145$).

Recruitment to CFAS II took place between 2008 and 2011 using the same strategy as for CFAS I. In total, 7796 participants were recruited from three of the original CFAS I locations in England. There was no repeated sampling from Liverpool. Furthermore, a separate but linked study in the Gwynedd area between 2011 and 2013 (CFAS II Wales) was not included in this analysis.

For the comparative analysis, to examine change between CFAS I and CFAS II, the analysis sample was restricted to the same age group (i.e. those aged ≥ 75 years) and centres (Cambridgeshire, Newcastle, Nottingham). Individuals living in residential or care homes were excluded from each sample as some services are provided by the residential and care homes themselves (CFAS, $n = 109$, CFAS I, $n = 197$). In total, 1619 and 3984 individuals from CFAS I and CFAS II, respectively, were included in the comparative analysis.

Ascertainment of health conditions and service use

Dementia was diagnosed using the Geriatric Mental State – Automated Geriatric Examination for Computer Assisted Taxonomy (GMS-AGECAT).[81] This standardised interview provides high agreement with the *Diagnostic and Statistical Manual of Mental Disorders*-Fourth Edition[82] (DSM-IV) criteria (kappa = 0.86) [see http://allpsych.com/disorders/dsm/ (accessed December 2015)]. When it was not possible to determine a diagnosis of dementia using the GMS-AGECAT, a diagnostician would provide a study diagnosis using DSM-IV criteria. Cognitive function was assessed using the Mini Mental State Examination (MMSE).[83]

Health conditions were self-reported by the individual or by an informant if a proxy interview was conducted. The conditions assessed included stroke, diabetes, VI, hearing difficulties, angina, heart attack, transient ischaemic attack, peripheral vascular disease, hypertension, Parkinson's disease, anaemia and breathing difficulties with a focus on stroke, diabetes and VI. In line with other parts of the study, the impact of three exemplar 'target' conditions was considered to help determine the influence of comorbid dementia on service use. These were diabetes, stroke and VI.

All services, including health, social and informal care, were self-reported (or informant reported in CFAS II) with questions focusing on use of day-to-day services (e.g. home help, meals on wheels), service use in the 4 weeks prior to interview [e.g. day centre, social worker, general practitioner (GP)] and hospital service use (e.g. day hospital, inpatient). Use of unpaid care was considered separately for the analysis.

Statistical analysis

The analysis was undertaken in two stages. First, a comparative analysis compared service use one decade apart using data from both CFAS cohorts, restricting the sample to those aged ≥ 75 years in the CFAS II cohort (sample size: CFAS I, $n = 1619$; CFAS I, $n = 3984$). Second, a detailed analysis was conducted in CFAS II (sample size, $n = 7796$). Both analyses were conducted on those living in the community, with those living in residential or nursing homes excluded, as some services are provided by the residential and nursing homes themselves. Although service user data were collected from both the respondent and the informant interviews in CFAS II, data were collected from only the respondent interviews in CFAS I. Therefore, to ensure comparability, only respondent information was used in the comparison analysis.

Prevalence estimates with 95% confidence intervals (CIs) were generated for service use and the comorbidities considered. Logistic regression was used to estimate service use by individuals with dementia and a comorbidity in comparison to service use by (1) those with dementia alone and (2) those with the comorbidity alone. All models were adjusted for age and sex. Estimates were inverse probability weighted in both CFAS I and CFAS II to account for the oversampling of those aged ≥ 75 years and the differences in age, sex and deprivation in those who participated. As the CFAS I analysis was conducted with the 10-year follow-up wave, the analysis also had to be weighted for attrition based on age, sex, stroke, diabetes, VI and latest cognitive status (using the MMSE).

Phase 2: focus groups and interviews

In phase 2 we addressed research questions 2 and 3 (see *Chapter 1*) through in-depth semistructured interviews with service users with a long-term condition and their family carers and focus groups or interviews with staff who organise and deliver care in a range of different specialities. This included:

(a) people diagnosed with dementia who had at least one of our target non-dementia-specific health-related problems (i.e. stroke, diabetes and VI)
(b) family/unpaid carers of people with dementia and one of our target non-dementia-specific health-related problems
(c) clinicians in both primary and secondary care who organised and delivered care for people with stroke, diabetes and VI.

Sampling

People with dementia and their family carers were recruited from two geographical regions: (1) the area covered by North Thames Clinical Research Network Dementias and neurodegeneration (DeNDRoN) (including the London boroughs north of the Thames, South Bedfordshire, Hertfordshire and Essex) and (2) the north-east of England (Newcastle). HCPs were also primarily recruited from these areas although focus groups were also held in Cambridgeshire and Leicestershire. We aimed to carry out 15–25 interviews per site with people with dementia and their family carers and a total of six focus groups across the sites to capture the different experiences of primary and specialist service professionals.

Recruitment of patients and family carers

Older people with a diagnosis of dementia with at least one of the target comorbid conditions (i.e. stroke, diabetes and VI) were recruited for the study. We also recruited family carers of people with dementia with at least one of the target comorbidities. Participants were purposively sampled to capture our specified comorbid conditions and a range of experience along the dementia pathway.

As stated above, recruitment took place in two geographical regions: the south-east of England (University of Hertfordshire) and the north-east of England (Newcastle University). In the south-east, participants were recruited through the North Thames Dementia Registry, general practices, local memory clinics in Hertfordshire and Bedfordshire and voluntary organisations (i.e. the Alzheimer's Society, Thomas Pocklington Trust and Stroke Association). In Newcastle, participants were recruited through general practices and the North East DeNDRoN patient list. Participating general practices identified potentially eligible participants for the relevant long-term illnesses (i.e. dementia, diabetes) from the practice Quality and Outcomes Framework (QOF) registers. This list was then screened by one of the practice GPs to identify those who met the inclusion criteria.

Potentially eligible participants were approached via an invitation letter from DeNDRoN or from the appropriate gatekeeper (such as a GP or memory clinic clinician). Invitation letters were accompanied by an information sheet and a reply slip for those who were interested in taking part in the study. Participating patients were asked whether or not they received any significant help from an informal carer and, if so, permission was sought from patients to invite the carer for interview. Participants who expressed an interest in participating were contacted by one of the research team to discuss the study further and arrange a time and place for the interview.

Inclusion and exclusion criteria for people with dementia and family carers

Inclusion criteria

- Having a range of experiences along the dementia pathway.
- Similar numbers with each of the target conditions of stroke, diabetes and VI.
- More than one comorbidity (e.g. stroke and heart disease) as long as one of the comorbidities was a target condition.
- Any type of dementia but excluding mild cognitive impairment (MCI).
- A confirmed diagnosis of dementia or taking dementia medication.
- Stroke – confirmed diagnosis from secondary care (regardless of aetiology).
- Diabetes – confirmed diagnosis of type 1 or type 2 diabetes.
- VI – defined as being registered blind or partially sighted or having a secondary care diagnosis of a condition that leads to VI, for example cataracts or macular degeneration.
- Interviews could be paired (person with dementia and his or her carer) or with the person with dementia or the carer alone.

Exclusion criteria

- Unable to speak English.
- Terminally ill or on the palliative care register.

Recruitment of health-care professionals

Clinicians in both primary and secondary care who organised and delivered care for people with stroke, diabetes and VI were recruited for interviews or focus groups. Individuals were purposively sampled to capture a range of experiences and interests. This included GPs with a specialist interest in long-term conditions, secondary care doctors at consultant or senior registrar level who specialised in the care of people with stroke, diabetes or VI and clinical nurse specialists/therapists and practice nurses responsible for the management of people with long-term conditions such as diabetes. Potential participants were identified and recruited through the clinical networks of the Research Management Group and the Advisory Group and through local clinical research networks.

Procedures

The focus of data collection was to identify characteristics of services that respond appropriately to patient and carer needs, positive and negative examples of patient care, areas where patient needs are not met and barriers to and facilitators of effective service provision for people with dementia and a comorbid condition. It enabled us to explore how the presence of dementia impacts on clinical decision-making processes. Different interview schedules/focus group prompts were designed for use with patients, carers and clinicians and according to the comorbidity involved (see *Appendix 2*). Interview and focus group schedules were guided by literature from the scoping study and consultation with members of the User Reference Group and were further refined based on content and findings from early interviews. Ethical approval was obtained from the National Research Ethics Service Committee East of England (Research Ethics Committee reference 13/EE/0091).

Interviews with service users

Most interviews with service users took place in the participants' own home, with one interview taking place in a participating memory clinic. Initially, the researcher introduced herself to the participant and explained that the study was looking at how memory problems affect how people manage other health conditions, for example diabetes, stroke or sight loss. Participants were given a copy of the study information sheet, which provided contact details of the research team, and a consent form, which they were asked to read and sign. Permission to record the interview was requested and it was explained to participants that the interview would remain anonymous and confidential. Participants were informed that they could have a break from the interview or withdraw at any time.

Once consent had been obtained, the researcher gathered demographic information (age, education level, previous employment, family support, social services support) for both the PLWD and the family carer. In addition, consent was obtained from participants for the researchers to contact their HCP (e.g. GP or doctor at a memory clinic) to obtain information about the type of dementia that they had been diagnosed with. The semistructured interview schedule was designed to gather information about the patients' health conditions; how they managed their conditions; their health-care experiences relating to their target comorbidities; the range of services used; and their views about what was working well or what they thought could be improved. The interview schedule was adapted according to the comorbidities involved. At the end of the interview the participants were asked if they had any questions and were given a £10 voucher in appreciation of their time.

Interviews and focus groups with service providers

Five focus groups with HCPs were conducted in the clinical setting, with each lasting for about an hour and facilitated by two researchers. For the interviews, one was conducted face to face and the rest were conducted by telephone, with interviews lasting for up to 30 minutes. The focus groups and telephone interviews followed the same procedures. HCPs were given the study information sheet together with a consent form to sign. The researchers requested permission to audio tape the sessions, explaining that all data would remain anonymous and confidential. After a brief description of the study, participants were asked to introduce themselves and describe their current role. The discussion focused on how dementia impacted on their service and clinical decisions; ways to improve services for people with dementia and comorbidities; care pathways and clinical guidance; and knowledge gaps for HCPs in non-dementia services.

Analysis

Qualitative data analysis drawing on thematic content analysis[84] was used to enable key features of patients', carers' and clinicians' experiences to be elicited from the data. Two (out of three) researchers (AB, FB, MP) independently scrutinised and coded a selection of transcripts. They compared codes and discrepancies were resolved by discussion.[85] Members of the User Reference Group also read several transcripts and met with the researchers involved in the qualitative data analysis to discuss the emerging themes. Emerging themes were also discussed with the Research Management Group and the Advisory Group. A coding framework, guided by the different characteristics of continuity of care and access to care, was developed and transcripts were entered into NVivo software (version 10; QSR International, Warrington, UK) for further qualitative data analysis. We used a constant comparison method to look for similarities and differences between patients, carers and clinicians and between different conditions.

Phase 3: development of ideas/recommendations

Consensus conference

The findings from the first two phases of the study were discussed with key stakeholders at a consensus conference. The purpose of consulting with stakeholders in this way was to validate the findings and assist in the development of guidance. Participants invited to the meeting included clinicians and service user representatives who took part in focus groups or interviews; members of the Research Management Group, Advisory Group and User Reference Group; practitioners specialising in the care of people with our target comorbidities (diabetes, stroke and VI); service managers and commissioners; and representatives from the third sector involved in supporting people with dementia (e.g. Alzheimer's Society, Carers in Herts) or people with our target comorbid conditions (e.g. Stroke Association, Diabetes UK, Thomas Pocklington Trust). The meeting began with a presentation from the research team that drew on the findings from the study. The presentation covered what is known about the impact of dementia on the receipt of non-dementia health services; barriers to and facilitators of service delivery for people with dementia and comorbidities; and evidence around best practice/effective care for service delivery for people with dementia and a comorbid medical condition. This was followed by a group discussion on the implications of the findings.

Nominal group technique

To structure the discussion and rank the importance of the findings and their relevance for service improvement and delivery we used a nominal group technique. A nominal group technique is a process that promotes the generation of ideas to develop a set of prioritised ideas/recommendations, enabling the participation of all group members and preventing the domination of one or two participants in the discussion. The process involves four stages: (1) the generation of ideas, (2) the recording of ideas, (3) discussing ideas and (4) prioritising ideas.[86,87] The nominal group technique was used to enable stakeholders, including members of the public, to meaningfully participate in the development of ideas/recommendations.

Participants were split into four groups (seven to nine participants in each) based on their area of specialty (i.e. stroke, diabetes, VI, general practice). Two service user representatives were placed in each group, one from the Public Involvement in Research Group at the University of Hertfordshire and the other from a dementia voluntary organisation (e.g. Alzheimer's Society, Dementia UK). Each group included two members of the research team, one to facilitate the group and one to take notes. The facilitator directed the discussion and focused attention on achieving a common understanding of the questions and their answers.

Based on the evidence presented and their own experiences, participants were asked to consider what changes they would recommend to improve care for people with dementia and comorbidity. They were told that this could be general or specific to one of the three target comorbidities. To stimulate free thinking of ideas, participants were told that no ideas were bad ideas and that they should not be restricted by cost, current systems or time frames. They were told that ideas/recommendations could be easily achievable or could be challenging to implement. To encourage a quick generation of ideas, participants had just 10 minutes to write their ideas/recommendations onto the ideas templates (see *Appendix 3*). The template required participants to name their idea, give a brief explanation and identify the barriers to and facilitators of the idea/recommendation.

After the generation of ideas, the group moderator asked the participants one by one to share one of their ideas/recommendations and these were recorded by the note taker. Each idea/recommendation was discussed, specifically focusing around how these concepts could be developed and implemented. The participants discussed and prioritised the ideas and decided which two they would present to the wider group. The note taker recorded the two ideas (agreed by the group) on large A3 templates in the centre of the table. These were discussed further to develop the ideas more fully (name the idea, explain the idea, benefits, barriers). Finally, the conference facilitator consolidated the ideas/recommendations by asking each of the tables (diabetes, stroke, VI and general practice) to put forward their 'best idea' to the larger group. Ideas/recommendations were discussed and recorded on a flip chart at the front of the room.

After the meeting ideas were summarised and grouped around key ideas or themes, such as integration, information sharing, carer support and education and training. They were also categorised into whether they related to primary or secondary care and if they were specific to one of our comorbidities. A report of the findings from the consensus meeting was circulated to all participants for feedback.

The development of ideas/recommendations

The findings of the scoping review, the results of the interviews and focus groups, and the outputs from the consensus meeting were used as a basis to map current models of care and to identify interventions that had the potential to support continuity and equity of access to care for people with dementia and comorbidity. After this mapping we ran searches in PubMed, Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects and Google Scholar to identify systematic reviews evaluating the models of care identified (e.g. case management, carer support, integration) (see *Appendix 1* for search terms). From this we developed ideas/recommendations about how services should engage with PLWD and their carers, indicators of quality that could inform the commissioning of services for older people and specialty-specific guidance on assessment and decision-making.

Patient and public involvement

A well-established Public Involvement in Research Group at the University of Hertfordshire has a broad membership of service users and carers. A member of this group chaired the project Advisory Group. In addition, three members of the Public Involvement in Research Group were part of a study User Reference Group. This group was involved in guiding the development of the interview schedule, guiding and challenging our interpretation of the qualitative findings and facilitating understanding of the implications for continuity from a service user perspective. Four members of the Public Involvement in Research Group attended the consensus conference in phase 3.

Chapter 4 Results of the scoping review

An earlier version of this review has been published elsewhere.[59] Since then the review has been updated to include an additional 12 papers.

Description of studies

We included 86 papers, 76 of which were classified as primary references[1,2,12,14,20,21,69,72,88–155] and 10 of which were classified as associated papers.[4,73,74,156–162] An overview of the selection process can be seen in *Figure 2*. Studies had been conducted in 12 different countries but 61% were from the UK and USA. The majority of the studies were observational or qualitative studies or reviews. Participants were predominantly community dwelling although some studies included mixed samples and those living in long-term care. The majority of studies included people with an average age of > 70 years. Ethnicity was not reported in 55% ($n = 42$) of studies. In 63% of studies ($n = 47$) all of the participants had dementia,[1,2,12,14,69,72,89–94,96,98,99,102,105,108,110–112,116–118,122,123,125,127,129,130,133,136–139,142,144–149,151,153–155] in 24% ($n = 18$) the studies included mixed populations including people with dementia, cognitive impairment and delirium[88,95,100,104,106,107,109,113,115,119,121,126,128,131,132,134,135,143] and in 13% ($n = 10$) participants had cognitive impairment or MCI.[20,21,101,103,114,120,124,140,141,150] In the remaining study[152] the focus was on clinicians' attitudes rather than people with dementia. In total, 44 studies[20,21,69,72,89,90,92–96,98,100,102–104,108,112,114–117,122,126,129,130,133,136–141,144–147,149–152,154,155] (58%) focused on a single comorbidity and the rest of the studies focused on more than one comorbidity or on general comorbidity/multimorbidity (e.g. papers relating to the experiences of people with dementia in acute hospitals). Most of the evidence related to prevalence and quality of care, with less evidence on service organisation and delivery or views and experiences of patients, carers or HCPs. The study characteristics are summarised in *Table 1* and details of the individual studies, including the links between primary and associated papers, are provided in *Appendix 4* (see *Table 12*).

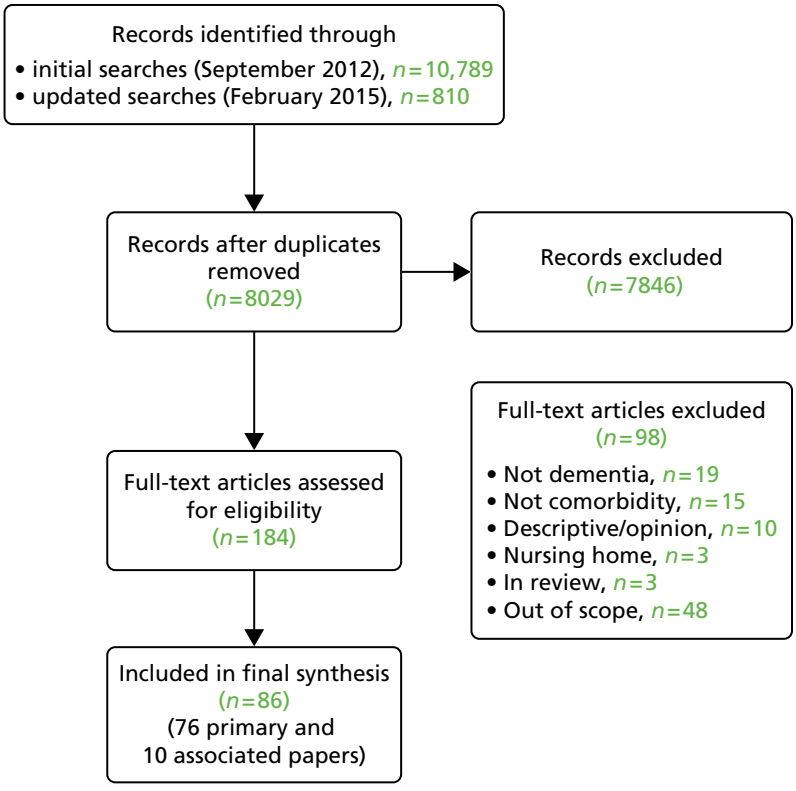

FIGURE 2 Flow chart detailing the study selection process.

TABLE 1 Overview of study characteristics ($n = 85$ papers)

Characteristic	Details[a]
Study information	
Year of publication, range	1989–2015
Country, *n*	
UK	26
USA	20
Europe (not UK)	10
Australia	3
Canada	5
Japan	2
International reviews/guidance	10
Type of study, *n*	
Case–control	8
Cohort study	13
Cross-sectional	19
Guideline/policy document	4
Qualitative	8
RCT	3
Survey	4
Review/scoping	11
Other	6
Areas covered in study, *n*[b]	
Prevalence	30
Service organisation and delivery	17
Views and experiences	13
Access to care	25
Setting, *n*	
Hospital/outpatient clinic	34
Community	15
Primary care	7
Mixed community/residential care/hospital	7
Population-based sample	8
Not specified (e.g. review)	5

TABLE 1 Overview of study characteristics ($n = 85$ papers) (*continued*)

Characteristic	Details[a]
Type of participants	
Type of cognitive impairment, *n*	
Dementia	47
Mixed populations	18
MCI or cognitive impairment	10
Age (years)	Range 43–102 but majority > 70; of 38 studies that gave a mean age, majority was in 70s
Ethnicity, *n*	
Not specified	41
White (or majority white)	15
Mixed	4
Mixed but majority black	2
NA (e.g. review)	14
Comorbidities included in studies[b]	
Diabetes	16
Stroke	9
VI	14
Other comorbidities (e.g. cancer, MI, hypertension)	8
General comorbidity	15
More than one comorbidity (but includes one of our target conditions)	14
Type of dementia	
Alzheimer's disease	8
Mixture of different types	5
Not reported	63

MI, myocardial infarction; NA, not applicable.
a All numbers refer to the numbers of studies not the number of individual participants.
b Some studies were classified in more than one category.

Prevalence

Our main aim was to look at the prevalence of comorbidity (in particular stroke, diabetes and VI) in people with dementia. Fourteen studies[1,2,12,14,91,118,119,121,127,128,137,142–144] provided data on the prevalence of comorbidities in people with dementia and two studies[101,134] provided data on the prevalence of comorbidities in people with MCI (*Table 2*).

The representativeness of the samples varied. Four studies[101,118,119,134] included population-based samples seven[1,2,14,91,121,127,144] recruited populations from primary care databases and five[12,128,137,142,143] used samples from hospitals or outpatient clinics (see *Appendix 4*, *Table 13*). Data were collected from medical records in seven studies,[12,14,91,127,137,142,144] from clinical examination or interviews in six studies[1,101,118,119,128,134] and from a mixture of medical records and clinical examination in three studies.[2,121,143] The presence of dementia and comorbid medical conditions was assessed using a variety of measures (see *Appendix 4*, *Table 14*).

We also included a further nine primary studies[20,95,103,104,129,140,141,145,146] and one systematic review[69] that reported the prevalence of dementia in people with one of our three target comorbidities (*Table 3*); five studies[20,95,103,104,145] included people with diabetes, three[69,129,146] included people with stroke and two[140,141] included people with VI. Three studies[103,140,141] included samples from outpatient clinics, one[20] included data from a RCT in primary care, two included data from research administration or health claims databases in the USA[104] and Australia,[145] one[129] included data from a stroke register in Canada, one[95] included a population-derived community-based sample in Australia and one[146] included data from a population-based register of vascular events in the UK. Three studies[104,129,145] collected data from medical or database records and the rest collected data from face-to-face interviews or clinical examinations.

Prevalence of target comorbidities in people with dementia

Diabetes

Thirteen studies reported the prevalence of diabetes in populations of people with dementia[2,12,14,91,118,119,121,127,128,142,143] or MCI.[101,134] Prevalence rates varied from 6% to 39%. A visual representation of the prevalence of diabetes in PLWD is provided in *Figure 3*. The two largest studies, both of which involved participants from national primary care data sets in the UK, one from Scotland[91] and one from the UK (primarily England),[127] reported similar prevalence rates of 13%[91] and 14%.[127] A Spanish study[14] reported a prevalence rate of 20% in men (95% CI 18% to 22.5%) and 16% in women (95% CI 14% to 17%). Although diabetes was one of the most frequent comorbidities in the study, the authors did not demonstrate a significant association between dementia and diabetes. Five studies compared rates of diabetes in those with and those without dementia. Three studies with samples recruited from primary care databases, two from the USA[2,121] and one from the UK,[127] found similar rates of diabetes between groups and a study in hospital inpatients in Switzerland[143] found no significant difference in the rate of diabetes between those with and those without dementia. In contrast, a study of hospital inpatients in the UK[12] found significantly fewer people with dementia diagnosed with type 2 diabetes than control subjects without dementia.

Stroke

Ten studies[2,12,14,91,118,119,121,127,142,143] reported the prevalence of stroke in people with dementia and two studies[101,134] reported the prevalence of stroke in people with cognitive impairment. Prevalence rates varied from 3% in hospitalised older people in the UK[12] to 34% in a sample of urban and rural community-dwelling people with cognitive impairment in the USA (*Figure 4*).[101] Two studies used records from large primary care databases in the UK, with one reporting that the rate of stroke in PLWD was 19%[91] and the other reporting that the rate of cerebrovascular disease (including stroke) was 29%.[127] A study using a primary care data set in Spain found a prevalence of cardiovascular disease of 7% in men and 5% in women.[14] Five studies compared the rate of stroke in people with and without dementia. Three[2,12,143] found no significant difference in the prevalence of stroke but one study of hospital inpatients[119] found that stroke was more common in people with dementia and a primary care-based study in the UK[127] found a greater prevalence of cerebrovascular disease in people with dementia.

TABLE 2 Prevalence of diabetes, stroke and VI in people with dementia

Study and country	Study type	Dementia/ cognitive impairment	Control/ comparison	Eligibility criteria	Recruited from	*n* whole sample	*n* dementia/ cognitive impairment	Diabetes (%)	Stroke (%)	VI (%)	Notes
Barnett *et al.*, 2012,[91] UK (Scotland)	Cross-sectional	Dementia	NA	Alive, permanently registered with a participating practice	Primary care – national data set	1,751,841	11,139	13.3	18.8	3.8	
Doraiswamy *et al.*, 2002,[1] USA	Cross-sectional	Dementia	NA	Diagnosis of Alzheimer's disease, age ≥ 50 years	Community health-care sites	679	679	–	–	–	61% had three or more comorbidities and 30% had vascular or heart disease. Sample included mixture of community-dwelling and long-term care participants
Feil *et al.*, 2003,[101] USA	Longitudinal cross-sectional	Cognitive impairment	No cognitive impairment	Geographically defined, age ≥ 65 years	Population-derived sample	7482	1774	26	34	–	
Heun *et al.*, 2013[12] UK	Retrospective case–control	Dementia	No dementia	Diagnosis of Alzheimer's disease, age ≥ 70 years, inpatient care for at least 24 hours	Hospital inpatients	72,878	634	6	3	1	VI was glaucoma. Diagnosis of diabetes was less common in those with Alzheimer's disease than in control patients (RR 0.7, 95% CI 0.5 to 0.9). No significant difference in prevalence of ischaemic stroke (RR 1.3, 95% CI 0.9 to 2.0) or glaucoma (RR 2.0, 95% CI 1.0 to 4.3)
Jara *et al.*, 2011[144] UK	Retrospective cohort	Dementia	No dementia	Age ≥ 64 years, at least 24 months' enrolment, no cataract diagnosis at baseline	Primary care – national data set	650,325	8124	–	–	–	Lower rate of any cataract in Alzheimer's disease group than in control group (HR 0.52, 95% CI 0.47 to 0.58)
Löppönen *et al.*, 2004,[118] Finland	Cross-sectional	Dementia	NA	Geographically defined, age ≥ 65 years	Population based	1260	112	16	24	29	PLWD less likely to be diagnosed with glaucoma (OR 0.36, 95% CI 0.15 to 0.86); no difference in rates of cataract ($p = 0.287$)

continued

TABLE 2 Prevalence of diabetes, stroke and VI in people with dementia (*continued*)

Study and country	Study type	Dementia/ cognitive impairment	Control/ comparison	Eligibility criteria	Recruited from	*n* whole sample	*n* dementia/ cognitive impairment	Diabetes (%)	Stroke (%)	VI (%)	Notes
Lyketsos *et al.*, 2005,[119] USA	Case–control	Dementia/ cognitive impairment	No dementia/ cognitive impairment	Geographically defined, age ≥ 65 years	Population based	695	374	20	16	–	Stroke more common in people with dementia ($p < 0.001$)
McCormick *et al.*, 1994,[121] USA	Case–control	Dementia/ cognitive impairment	No dementia/ cognitive impairment	Age ≥ 60 years, member of HMO, geographically defined	HMO database	154	154	6	3[a]	10	Vision problems less common in PLWD (10% vs. 24%)
Poblador-Plou *et al.*, 2014,[14] Spain	Cross-sectional	Dementia	No dementia	Age ≥ 65 years, consulted physician at least once during the 12-month period of the study	Database of 19 primary health-care centres	72,815	3971	20 M, 16 F	7 M, 5 F	7 (M and F)	Cataracts 7%, glaucoma 4% in M and F
Rait *et al.*, 2010,[127] UK	Cohort	Dementia	No dementia	Age ≥ 60 years with first code for dementia during the study period, at least 6 months of data	Primary care – national data set	135,174	22,529	14	29[a]	–	No difference in prevalence of diabetes (13.9% vs. 14.5%) but cardiovascular disease more common in people with dementia (29.3% vs. 13.3%)
Sakurai *et al.*, 2010,[128] Japan	Cross-sectional	Dementia/ cognitive impairment	NA	Dementia or MCI	Memory clinic	160	160	19	–	–	Dementia and CI
Schubert *et al.*, 2006,[2] USA	Cross-sectional	Dementia	No dementia	Age ≥ 65, seen primary care physician within 2 year. Excluded nursing home residents and non-English-speaking patients	Primary care	3013	107	39	10	–	No significant difference in prevalence of diabetes ($p = 0.19$) or stroke ($p = 0.89$) between those with and those without dementia
Stephan *et al.*, 2011,[134] UK	Cross-sectional	MCI	No MCI	Age ≥ 65 years	Population based	13,004	1486	7	19	–	

Study and country	Study type	Dementia/ cognitive impairment	Control/ comparison	Eligibility criteria	Recruited from	*n* whole sample	*n* dementia/ cognitive impairment	Diabetes (%)	Stroke (%)	VI (%)	Notes
Uhlmann *et al.*, 1991,[137] USA	Case–control	Dementia	No dementia	Age ≥ 65 years, English speaking, eighth grade of higher level of education, ability to complete audiometric evaluation	Adult medicine clinic	174	87	–	–	–	Prevalence of VI significantly higher in cases than in control subjects (OR 2, 95% CI 1.2 to 3.4)
Zamrini *et al.*, 2004,[142] USA	Case–control	Dementia	NA	Probable Alzheimer's disease, black or white (white participants matched non-randomly to black participants)	Memory clinic database	334	334	18	9	10	Includes all eye diseases
Zekry *et al.*, 2008,[143] Switzerland	Cohort	Dementia/ MCI	No dementia	Age ≥ 75 years. Excluded those with a terminal illness or disorders interfering with psychometric assessment	Hospital inpatients	349	188	19	22	–	MCI and dementia

–, not provided; F, female; HMO, health maintenance organisation; HR, hazard ratio; M, male; NA, not applicable; OR, odds ratio; RR, relative risk.
a Cerebrovascular disease.

TABLE 3 Prevalence of dementia in people with diabetes, stroke and VI

Study and country	Type of study	Type of population	Control/ comparison	Eligibility criteria	Recruited from	*n* whole sample	*n* dementia/cognitive impairment
Bruce *et al.*, 2003,[95] Australia	Longitudinal cross-sectional	Diabetes	NA	Defined by postcode, age ≥ 70 years, diabetes	Patients living in catchment area of hospital (63% of eligible patients recruited)	223	34 (15.2%)
Feil *et al.*, 2009,[103] USA	Longitudinal cross-sectional	Diabetes	NA	Diagnosis of type 2 diabetes, age ≥ 60 years	Geriatric clinic	51	23 (45%) cognitive impairment
Feil *et al.*, 2011,[104] USA	Cross-sectional	Diabetes	NA	Veterans aged ≥ 65 with diabetes	Research administration database (Veterans Health Administration)	497,000	65,107 (13%) dementia/cognitive impairment
Hewitt *et al.*, 2010,[20] UK	Questionnaire	Diabetes	NA	Type 2 diabetes, age ≥ 75 years, not resident in a nursing home	Data from RCT in primary care	1047	235 (22.4%) dementia/cognitive impairment
Pendlebury and Rothwell, 2009,[70] UK	Systematic review (73 studies)	Stroke	NA	Dementia and stroke measured by standard criteria	22 hospital-based and eight population-based studies (7511 patients)	NA	Pooled prevalence of pre-stroke dementia 14% in hospital-based studies and 9% in population-based studies. Post-stroke rates ranged from 7% to 41%
Pendlebury *et al.* 2015,[146] UK	Prospective cohort study	Stroke	NA	TIA or stroke; dementia defined as pre and post event	Register collected for study – data from primary care (nine GP practices)	1236	93 (8%) pre-event dementia, 173/1143 (15%) post-stroke dementia
Saposnik *et al.*, 2011,[129] Canada	Retrospective cohort study	Stroke and dementia	Stroke no dementia	Age ≥ 18 years, first ischaemic stroke	Stroke register (included patients admitted to 12 regional stroke centres in Ontario, Canada)	10,658	966 (9.1%)
Whitson *et al.*, 2010,[140] USA	Cross-sectional	VI (macular disease)	NA	Age ≥ 65 years, macular disease diagnoses	Low-vision rehabilitation clinic	101	19 (19%)
Yochim *et al.*, 2012,[141] USA	Case series	VI (glaucoma)	NA	Age ≥ 50 years, diagnosis of glaucoma	Glaucoma clinic	41	44% MCI
Zhang *et al.*, 2010,[145] Australia	Retrospective cohort study	Diabetes	NA	Veterans, age ≥ 65, received prescription for diabetes in previous 6 months	Health claims database	17,095	4.4%

NA, not applicable; TIA, transient ischaemic attack.

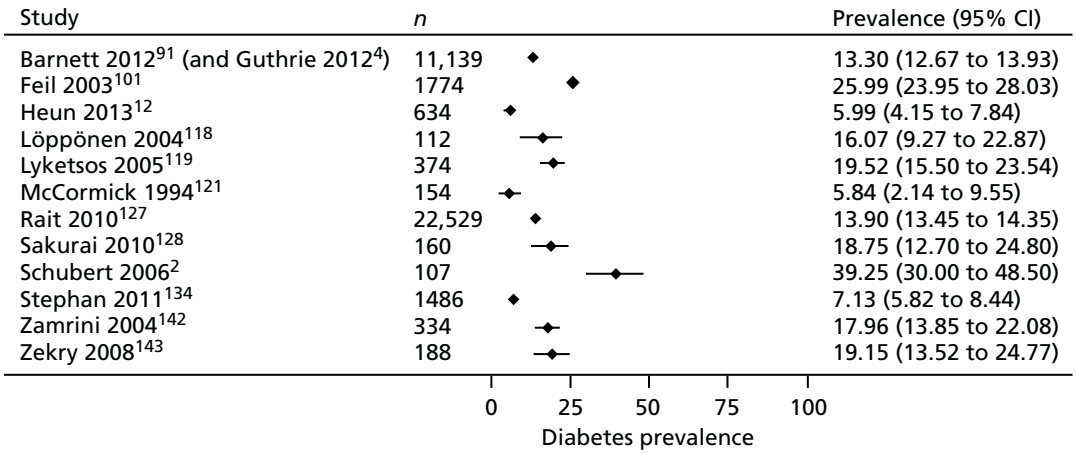

FIGURE 3 Prevalence of diabetes in PLWD.

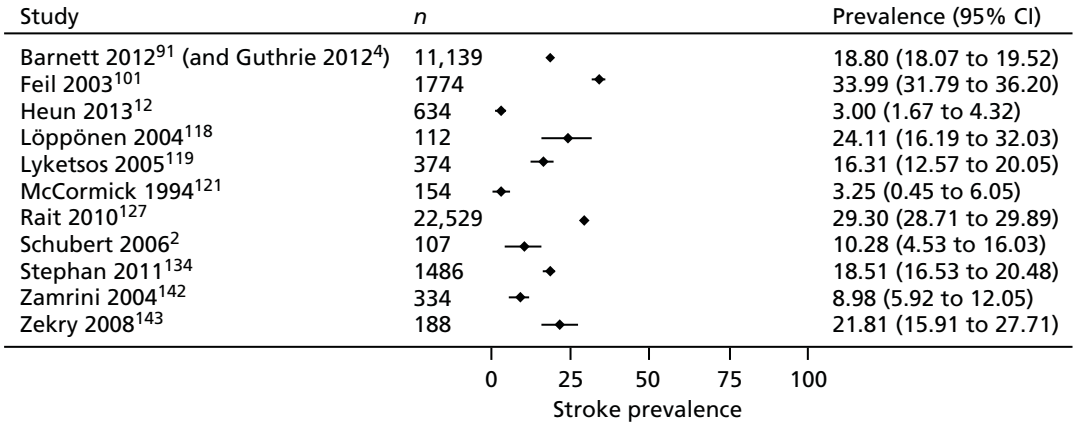

FIGURE 4 Prevalence of stroke in PLWD.

Vision impairment

Eight studies reported the prevalence of some form of VI in people with dementia, including all eye diseases,[91,121,137,142] glaucoma[12,14,118] and cataracts.[14,118,144] Differences in the populations studied and the way that cases were identified make comparisons across studies difficult. Two studies compared rates of glaucoma in people with dementia and those without dementia; prevalence in people with dementia was lower in a population sample in Finland[118] but no different in hospital inpatients in a retrospective case–control study in the UK.[12] Two studies compared rates of cataracts. A large primary care cohort study in the UK found a lower incidence rate for cataracts in people with Alzheimer's disease than in control subjects[144] but a smaller population-based study in Finland reported no difference in the rates of cataracts.[118] A cross-sectional study in Spain found that the prevalence of cataracts was 7% and that of glaucoma was 4%.[14]

Prevalence of dementia in people with stroke, diabetes and vision impairment

Ten studies[20,69,95,103,104,129,140,141,145,146] provided some data on the prevalence of dementia in people with one of our target comorbidities, but only eight provided data that could be included in a forest plot (*Figure 5*).

Five studies[20,95,103,104,145] looked at the prevalence of dementia or cognitive impairment in populations of people with diabetes. In a large population-based study in the USA,[104] 13% of people with diabetes had dementia or cognitive impairment whereas, in a UK sample recruited through primary care,[20] 23% of people with diabetes had dementia or cognitive impairment. Two studies reported the prevalence of dementia in people with VI recruited through eye clinics.[140,141] In one,[140] 19% of people with macular

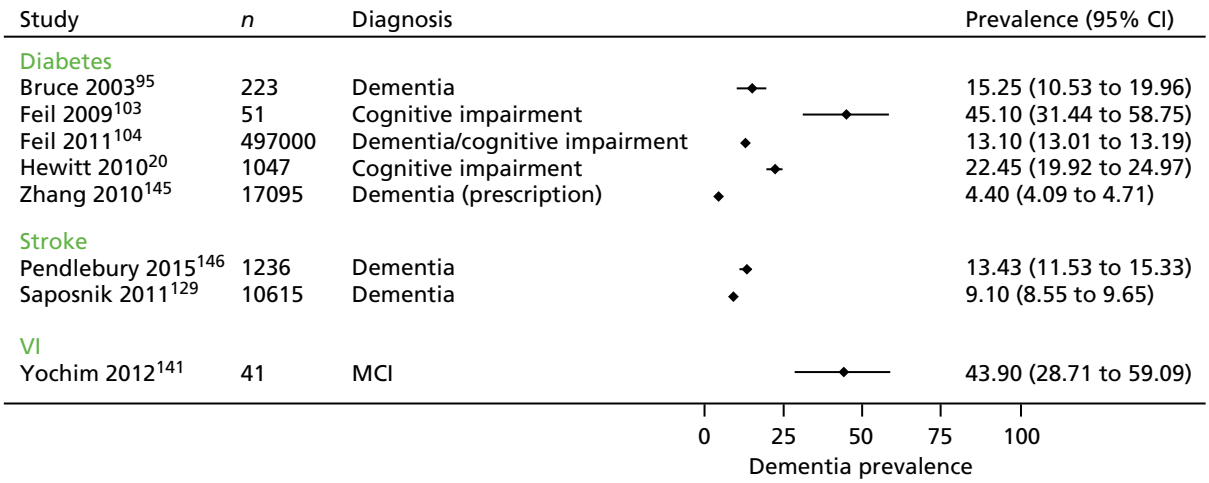

FIGURE 5 Prevalence of dementia/cognitive impairment in people with the target comorbidities.

disease had dementia and in the other,[141] 20% of people with glaucoma had memory impairment and 22% had impaired executive functioning.

Two studies[129,146] and one systematic review[69] looked at the prevalence of dementia among people who had had a stroke. Of over 10,000 people on a stroke register, 9% were reported to have dementia.[129] A study using hospital and primary care data in the UK[146] found a prevalence of pre-stroke dementia of 8% and of post-stroke dementia of 15% and a systematic review[69] reported a pooled prevalence of pre-stroke dementia of 14% in hospital-based studies and 9% in population-based studies. Post-stroke rates of dementia ranged from 7% to 41%.[69]

Access to care

We categorised 25 studies[21,90,98,100,103,104,110,111,114–118,123,129,130,136,139,145,150–152,154,155,161] as relating to access of care, for example comprehensiveness, equity and outcomes of care.

Comprehensiveness and equity

Eleven studies[98,110,117,118,123,129,136,139,145,155,161] compared access to treatment or receipt of services in groups with and without dementia. Ten[98,110,117,118,129,136,139,145,155,161] of the 11 studies found some evidence that people with dementia were less likely to receive the same quality of care or access to services as those without dementia. For instance, studies found that people with dementia were less likely to receive monitoring for diabetes-related problems[97,136] and had reduced access to treatment such as intravenous thrombolysis for stroke,[129] surgery for cataracts,[110] treatment for age-related macular degeneration (AMD)[98,117] or services for diabetes.[139,145] More details are provided in *Table 4*. In addition, a German study reported that older people with a greater number of comorbidities were less likely to receive cholinesterase inhibitors for dementia[111] and a Canadian study found evidence that pain is undertreated in people with dementia and arthritis.[90] In addition, a study from the USA[151] found that only 0.58% of a cohort of patients with acute ischaemic stroke (AIS) and dementia had received thrombolysis compared with a previous study which reported that 1.28% of all ischaemic stroke patients in the elderly population received thrombolysis.[163]

TABLE 4 Impact of dementia and medical comorbidities on quality of care and access to treatment

Study	Country	Comorbidity	Study type	*n* participants	Aspect of quality of care	Evidence that care is different	Reported differences in care/treatment
Connolly *et al.*, 2013[161]	UK	Diabetes, stroke	Cross-sectional	700 PLWD (compared with people without dementia on QOF register)	Monitoring and treatment	Yes	PLWD scored significantly lower on 73% of the QOF indicators, including peripheral pulses checks, neuropathy testing and cholesterol measures for stroke
Curtis *et al.*, 2012[98]	USA	VI (AMD)	Retrospective cohort	284,380	Treatment	Yes	PLWD were significantly less likely to receive anti-VEGF (RR 0.88, 95% CI 0.88 to 0.89)
Guijarro *et al.*, 2010[110]	Spain	VI, general	Cohort	40,482	Treatment	Yes	PLWD had some procedures less frequently than those without dementia, e.g. cataract surgery ($p < 0.001$), hernia repair, orthopaedic surgery
Keenan *et al.*, 2014[117]	UK	VI (AMD)	Cohort	65,894 AMD cohort, 168,092 dementia cohort	Treatment	Yes	PLWD showed a significant decrease in the likelihood of hospital admission for AMD ($p < 0.001$)
Löppönen *et al.*, 2004[118]	Finland	VI, general	Cross-sectional (survey)	1260 older people (112 PLWD)	Diagnosis and treatment	Yes	PLWD had more undiagnosed diseases than those without dementia ($p = 0.041$) and were less likely to be diagnosed with glaucoma ($p = 0.022$)
Müther *et al.*, 2010[123]	Germany	Diabetes, hypertension	Retrospective matched control	216 PLWD, 216 matched control subjects	Treatment	No	No significant differences in treatment for those with and without dementia. PLWD were more likely not to receive medication for hypertension (not significant)
Saposnik *et al.*, 2011[129]	Canada	Stroke	Cohort	877 pre-existing dementia, 877 control subjects (no pre-existing dementia)	Treatment	Yes	Patients with pre-existing dementia were less likely to receive intravenous thrombolysis
Sloan *et al.*, 2004[155]	USA	AMI	Cross-sectional	5851 AMI with dementia, 123,241 AMI no dementia	Treatment	Yes	PLWD were less likely to have a range of invasive procedures than those without a history of dementia

continued

TABLE 4 Impact of dementia and medical comorbidities on quality of care and access to treatment (*continued*)

Study	Country	Comorbidity	Study type	*n* participants	Aspect of quality of care	Evidence that care is different	Reported differences in care/treatment
Thorpe *et al.*, 2012[136]	USA	Diabetes, VI	Cohort	288,805 (44,717 PLWD)	Monitoring	Yes	PLWD were less likely to receive HbA_{1c} tests (73% vs. 81%), LSC-C tests (61% vs. 79%) and eye examinations (52% vs. 63%)
Vitry *et al.*, 2010[139]	Australia	Diabetes	Cohort	20,134 veterans with diabetes (includes people with dementia/cognitive impairment but numbers not clear)	Treatment	Yes	Presence of dementia was associated with a decreased likelihood of treatment intensification (e.g. addition of antidiabetic medicine or switch to insulin/different medication)
Zhang *et al.*, 2010[145]	Australia	Diabetes, VI	Cohort	17,095 veterans with and without diabetes (4.4% on dementia medication)	Treatment, access to services	Yes	Patients receiving medications prescribed for dementia were less likely to use diabetic and optometry/ophthalmology services

AMI, acute myocardial infarction; HbA_{1c}, glycated haemoglobin; LSC-C, low-density lipoprotein test; RR, relative risk; VEGF, vascular endothelial growth factor.

Outcomes

A number of studies looked at the impact of health-care treatments on health-related outcomes for older people with dementia or cognitive impairment. One systematic review[149] evaluated the evidence on the treatment of hypertension in older people with dementia. This review included six RCTs and concluded that, although there was evidence to suggest that antihypertensives are effective in lowering blood pressure in people with mild to moderate dementia, there was no consistent evidence of a benefit in terms of cognitive outcomes. Moreover, most trials excluded participants with substantial physical or mental health problems, which makes it difficult to generalise findings to those with more advanced dementia or multimorbidity.

Thrombolytic therapy for stroke

Although age is a known risk factor for stroke, most trials of intravenous tissue plasminogen activator (IV tPA) have excluded or under-represented patients aged > 80 years[154] and the impacts of thrombolysis in people with dementia are unclear. We found three observational studies[150,151,154] that had looked at outcomes in patients with dementia or cognitive impairment following thrombolysis for AIS. In one[154] the odds of death were increased in patients with pre-stroke dementia, which suggests that pre-stroke dementia is an independent predictor of in-hospital mortality after acute reperfusion therapy for stroke. However, this was a small retrospective analysis of 153 patients of whom only 21 had pre-stroke dementia. A prospective observational study in French and Japanese patients treated with IV tPA for cerebral ischaemia[150] found that patients with pre-stroke cognitive impairment had more symptomatic intracerebral haemorrhage and were less frequently independent 3 months after stroke than those without pre-stroke cognitive impairment, but they did not differ for any of the outcome measures after adjustment for age, baseline National Institutes of Health Stroke Scale score and onset to needle time. The authors concluded that, in patients with pre-stroke cognitive impairment presenting with AIS, IV tPA improves outcomes. A cohort study in the USA[151] identified admissions for AIS from a national database. Of 35,557 patients with AIS and a diagnosis of dementia, only 207 (0.58%) had received thrombolysis. The authors found that thrombolysis was associated with increased mortality and intracerebral haemorrhage in both those with and those without dementia and that the risks in both groups were similar. They concluded that the administration of thrombolysis for AIS in patients with dementia was not associated with an increased risk of intracerebral haemorrhage or death compared with their counterparts without dementia.

One survey of Canadian neurologists attempted to better understand the decision-making process surrounding the administration of IV tPA.[152] They found that 79% of respondents were less likely to administer IV tPA to patients with dementia and many were less likely to treat patients from nursing homes, those with more severe stroke or those aged > 80 years. Post-hoc subgroup analyses suggested that more experienced physicians – those in practice for > 10 years – were more likely to administer IV tPA to patients with dementia. However, this study did not explore why neurologists might be less likely to treat people with dementia.

Views and experiences

We included 13 studies looking at views and experiences of PIWD, their family carers and HCPs. Seven[72,92,102,125,132,148,162] were qualitative studies, one[107] was a mixed study including a review and a qualitative study, three[93,99,153] were reviews and two[20,94] were questionnaire studies. Three studies[20,94,102] focused on people with dementia and diabetes, two[72,93] focused on those with dementia and VI, one[89] looked at those with dementia and deafness, one[92] focused on those with dementia and cancer, two[148,153] looked at family carers' views on medication management and four[99,107,125,132] looked at the needs of people with dementia in general hospitals.

Literature on the experiences of older people with dementia in acute general hospitals has highlighted shortcomings in the care provided, the attitudes and training of staff, and the physical environment and problems with care cultures.[99,107,125] Poor communication is a major barrier to the provision of good care for people with dementia and a comorbid health condition.[72,99,107] Practitioners reported that they found it difficult to communicate with PLWD and communication difficulties were compounded when PLWD had additional comorbidities that made communication difficult, such as hearing loss or sight loss.[72,89,92] There were also problems with communication between different professionals and specialist teams, with a lack of co-ordinated working between practitioners in different specialities.[72] A lack of appropriate knowledge and training was also a major barrier, with those working in acute care hospitals,[107] palliative care[92] and diabetes[104] lacking knowledge about dementia. Conversely, those in dementia services may lack awareness about how to support people with dementia and VI.[72,158]

A qualitative study involving the views of 21 caregivers of people with dementia and type 2 diabetes found that behavioural and psychological symptoms of dementia disrupted diabetes care.[102] In addition, carers felt that they received inadequate support in planning their relatives' care, that their contribution to managing their relatives' care was not always recognised and that they were often excluded from decision-making. A systematic review[153] investigating the role of informal caregivers of PLWD found that family carers are often expected to manage medication regimens, the complexity of which are increasing. However, health-care systems and structures were often not helpful, for example family caregivers might not be included in communications about medication regimen changes and were not given the information and support that they needed to carry out their medication management roles. A focus group with carers of PLWD[148] found that carers felt unsupported by health and social care teams in terms of dealing with the practicalities of medication administration. There were also issues around the difficulties of recognising when a PLWD was no longer able to safely administer medication and ambiguity about where responsibility should lie for monitoring their use of medication.

Service organisation and delivery

Guidelines and care pathways

Current pathways for diabetes and other long-term conditions tend to focus on models of self-management. However, there is evidence that having dementia or cognitive impairment impacts on a person's ability to undertake self-care management. For example, people with dementia and diabetes had problems understanding their condition, managing medication and monitoring their blood glucose.[20,21,94,102,103] A review published in 2013[88] identified 16 guidelines/position statements or standards (from the UK, USA and Australia) for the care of PLWD but these generally focused on standards for providing optimal care for older people with cognitive impairment in acute hospitals or on specific issues such as hydration, nutrition or wandering. They did not cover issues relating to the care of people with dementia and specific medical conditions (such as stroke). Moreover, most models of practice for work with PLWD do not mention VI.[158]

Guidance on the care of older people with diabetes[112] highlights the need to balance the benefits of diabetes treatment while minimising the risks in people with dementia, as this group may be at increased risk of hypoglycaemia.[112,131] A National Expert Working Group[147] has recently published a best clinical practice statement relating to the management of diabetes in people with dementia. It has outlined a number of key principles of care for people with both diabetes and dementia. This includes regular reassessment to identify additional care needs, consideration of problems of adherence to therapy, use of 'safer' glucose-lowering medications and the recognition of when 'severe' dementia supervenes and priorities of management may need revision. Reduction in risk of hypoglycaemia should revolve around assessment of all risk factors for hypoglycaemia, identification of whether 'hypo' awareness exists, provision of tailored education, use of lower-risk glucose-lowering medications and adequate carer support. The statement suggests that diabetes specialists require training to ensure that they have the necessary competencies to identify and manage people with dementia and diabetes in a safe and supportive fashion.

Currently, there is little guidance for VI specialists when caring for PLWD, but the College of Optometrists[96] states that when examining patients with dementia optometrists have a duty to carry out whatever tests are necessary to determine their need for vision care. To date, most guidelines are condition specific and generally fail to take into account multimorbidity or the needs of people with dementia.[4,20,103,134,139,158]

Models of care for older people with cognitive impairment

A number of initiatives have been developed to improve the care of older people with dementia in acute hospitals, including liaison psychiatric services[113,135] or specialist units that combine medical and mental health care for older people.[106,109] Much of the work in this area is descriptive,[106] although a specialist medical and mental health unit for PLWD has recently been evaluated in a RCT in the UK.[109] This study randomised 600 patients aged > 65 years who were identified as confused on admission to either the specialist unit or standard care on a general medical ward. The authors found no difference in the primary outcome (days spent at home) but there were significant differences in process items in favour of the intervention and family carers were more satisfied. However, the study excluded patients with a clinical need for specialist services such as surgery or a stroke unit.

A scoping review of interventions for cognitively impaired older people in emergency departments found no evaluations of organisational or system-level interventions and little evidence of appropriate interventions.[124] We found no evaluations of interventions aimed specifically at our three target comorbidities, although a retrospective analysis of stroke patients suggested that cognitively impaired patients benefit from admission to an acute rehabilitation stroke unit.[126]

Conclusions

The prevalence of comorbid conditions in PLWD is high. Although current evidence suggests that PLWD may have poorer access to services for conditions such as stroke, diabetes and VI, the reasons for this are not clear. There is a need for more research looking at the ways in which having dementia impacts on clinical care for other conditions, how processes of care and different services can adapt to the needs of people with dementia and comorbidity and what interventions might improve access to services and the physical health of PLWD. Clinical guidance should consider the particular needs of those with dementia and comorbid health conditions, particularly when a concomitant diagnosis of dementia is common. In addition, there is evidence that, although family carers are frequently expected to take on responsibility for managing medication and other health-related tasks, they often feel poorly supported by HCPs.

Chapter 5 Results from the Cognitive Functioning and Ageing Studies analysis

Chapter overview

The first half of this chapter concerns analysis using data from CFAS II to examine the prevalence of each of the target health conditions (stroke, diabetes and VI) with and without dementia and service use across groups with dementia and any of the health conditions. The sample was restricted to those living in the community as some services would be provided by care homes for those living in care settings.

The results shown in the second half of the chapter are for the comparison analysis between CFAS I and CFAS II. This allows inferences concerning changes in patterns of service use between the turn of the century and a decade later. The analysis was restricted to the three CFAS II centres and, for the same reason as above, those living in the community. Questions on service use were introduced in the 10-year follow-up wave in CFAS I, which meant that all participants were aged ≥ 75 years and therefore CFAS II was also restricted to individuals aged ≥ 75 years.

Cognitive Functioning and Ageing Studies II analysis

Box 1 shows the key messages of this analysis.

Prevalence

The prevalence of each of the target conditions in people with and without dementia in the CFAS II sample (excluding those living in residential care) is shown in *Table 5*. For people with dementia, approximately one in six had all of the target health conditions and over one-third had at least one of the target health conditions. This compares to just under one-third for those without dementia. As expected,

BOX 1 Key messages

Prevalence

- Comorbid stroke, diabetes and VI are common in people with dementia.

Dementia and comorbidity compared with dementia alone

- Inpatient hospital services were used more by those with dementia and a target health condition.
- A chiropodist was used more by those with dementia and a target health condition.
- A home care assistant, day centre and care worker were used more by those with dementia and stroke.
- Any nursing service was used more by those with dementia and either diabetes or VI.

Dementia and comorbidity compared with comorbidity alone

- Unpaid care was used more by those with dementia and a target health condition.
- A home care assistant, day centre and care worker were all used more by those with dementia and a target health condition.

TABLE 5 Prevalence of target comorbidities in those with and without dementia living in the community

	Dementia[a]			No dementia		
Health condition	*n*	Weighted prevalence (%)	95% CI (%)	*n*	Weighted prevalence (%)	95% CI (%)
Stroke	58	17.8	13.6 to 23.0	536	7.7	7.1 to 8.4
Diabetes	53	16.5	12.5 to 21.6	999	14.0	13.2 to 14.8
VI	51	16.6	12.5 to 21.7	970	14.2	13.4 to 15.1
Target comorbidities	126	36.2	30.8 to 42.0	2173	30.8	29.8 to 31.9

a 5.3% of those in the community.

because of its strong causal link, the prevalence of stroke in patients with dementia was approximately 2.5 times greater than the prevalence in those without dementia. The prevalence rates for diabetes and VI were broadly similar between the groups.

Service use

Overall service use by presence of a target health condition is shown in *Figure 6* and across individual categories is shown in *Figure 7*. Additional details of relative differences in service use between the dementia alone group and the dementia with a target condition group are provided in *Appendix 5*.

Dementia and comorbidity compared with dementia

Approximately one-third of individuals with dementia and no target condition used hospital services in the last 12 months. In comparison, between 45% and 58% of individuals with dementia and one of the target health conditions used hospital services, with the highest use seen in those with dementia and stroke (see *Figure 6*). This was mainly driven by the use of inpatient services, as day patient and outpatient service use was largely the same in both groups (see *Figure 7*). Those with dementia and stroke used inpatient services more than those with only dementia; this was also the case for those with dementia and either diabetes or VI, but the level of service use was not quite as high as it was for those with dementia and stroke (see *Appendix 5*).

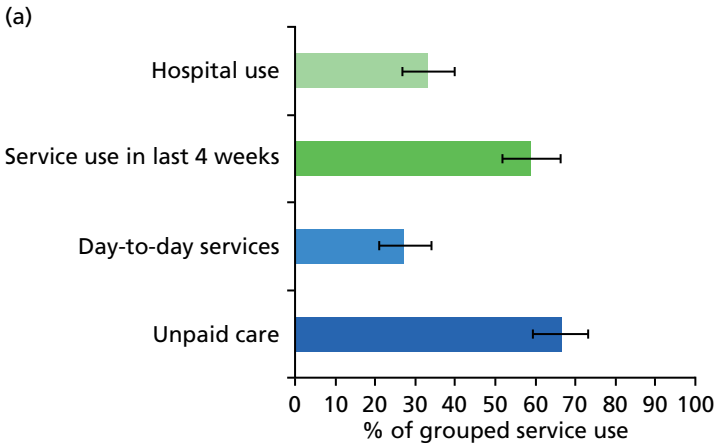

FIGURE 6 Percentage of grouped service use with 95% CIs by those with dementia only and those with dementia and a target comorbidity. (a) Dementia and no target comorbidity; (b) dementia and stroke; (c) dementia and diabetes; and (d) dementia and VI. (*continued*)

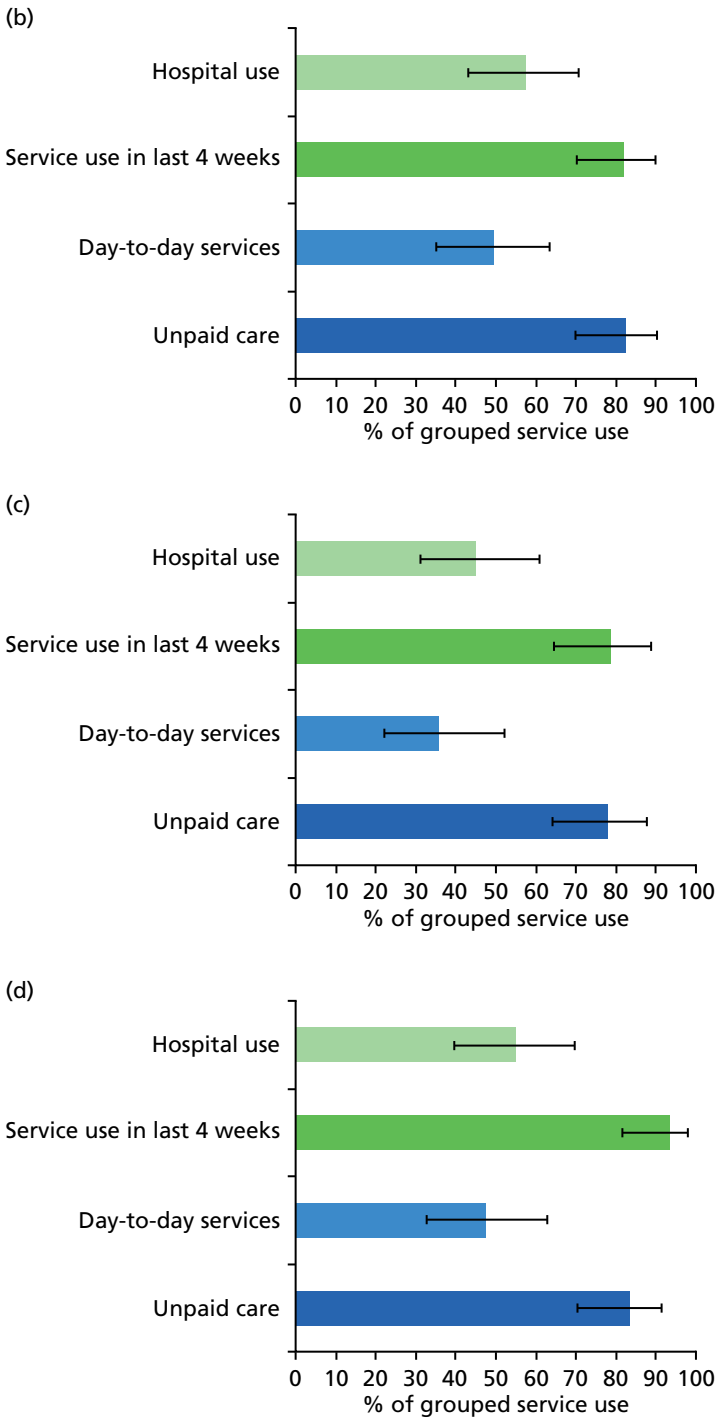

FIGURE 6 Percentage of grouped service use with 95% CIs by those with dementia only and those with dementia and a target comorbidity. (a) Dementia and no target comorbidity; (b) dementia and stroke; (c) dementia and diabetes; and (d) dementia and VI.

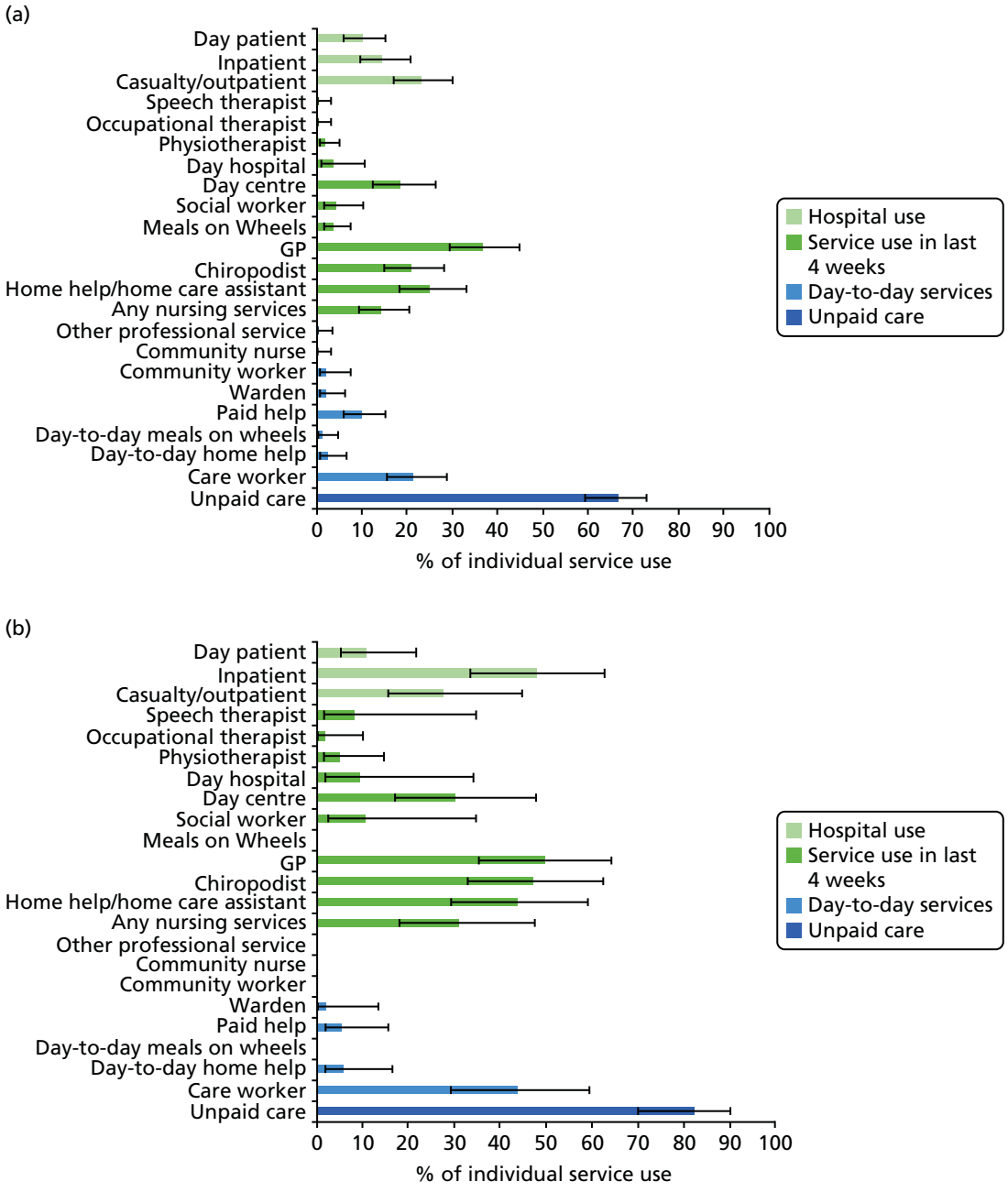

FIGURE 7 Percentage of individual service use and 95% CIs by those with dementia only and those with dementia and a target comorbidity. (a) Dementia and no target comorbidity; (b) dementia and stroke; (c) dementia and diabetes; and (d) dementia and VI. (*continued*)

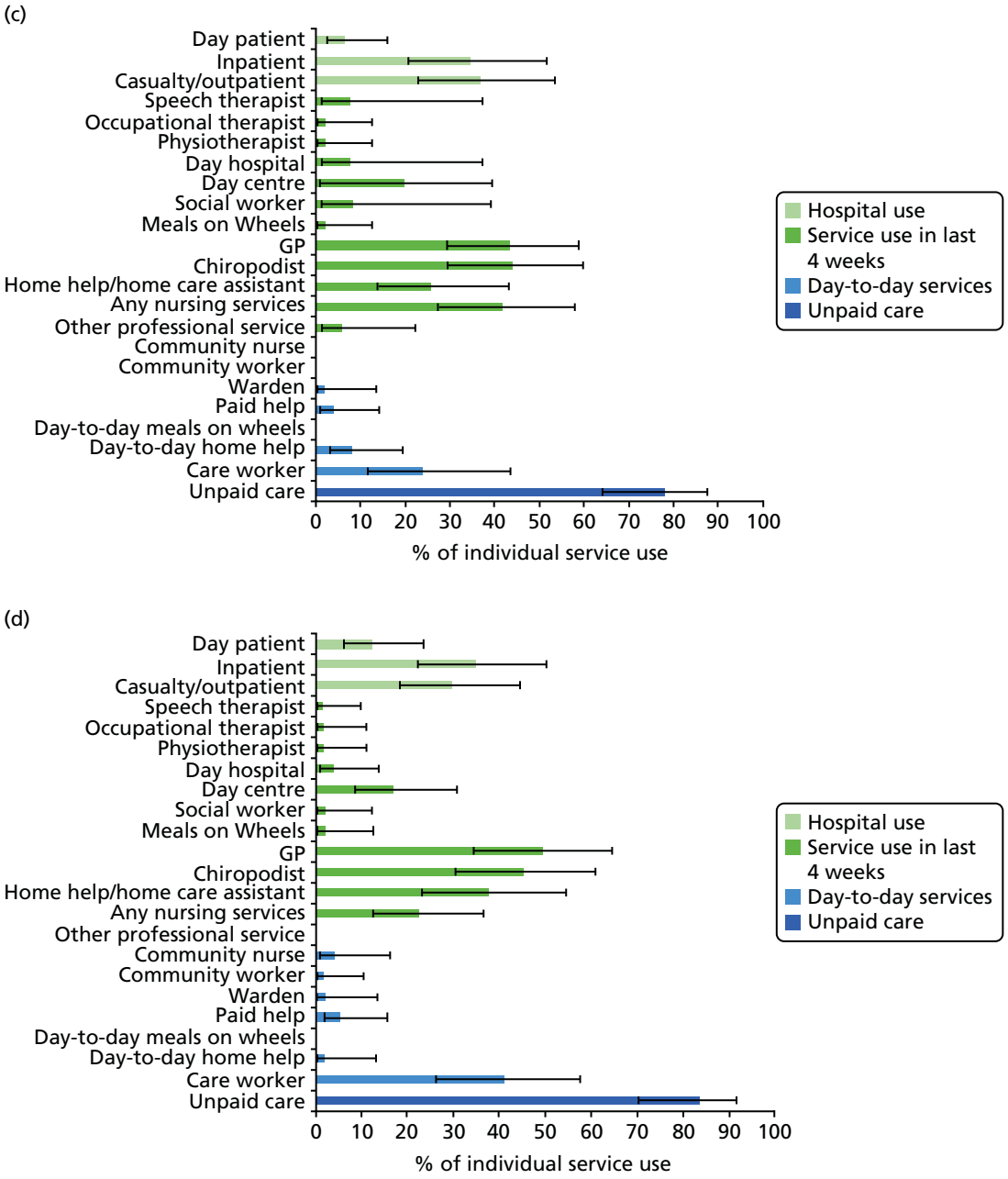

FIGURE 7 Percentage of individual service use and 95% CIs by those with dementia only and those with dementia and a target comorbidity. (a) Dementia and no target comorbidity; (b) dementia and stroke; (c) dementia and diabetes; and (d) dementia and VI.

As with hospital use, the use of services in the previous 4 weeks was higher for those with dementia and one of the target health conditions than for those with dementia alone (see *Figure 6*). For those with dementia but none of the target health conditions, six out of 10 people used some form of service in the last 4 weeks, whereas, for those with dementia and one of the target health conditions, around eight out of 10 people used some form of service in the last 4 weeks. Use of services was higher for those with dementia and stroke because of home care assistant, chiropodist and day centre use (see *Appendix 5*). The use of any nursing service and chiropodists was the reason for higher service use in the previous 4 weeks for those with dementia and diabetes and this was also the case for those with dementia and VI (see *Appendix 5*).

Around one-quarter of people with dementia and none of the target conditions used day-to-day services. This compared with more than one-third of those with dementia and diabetes and almost half of those with either dementia and stroke or dementia and VI (see *Figure 6*). Those with dementia and stroke had day-to-day help from a care worker a considerable amount more than those with dementia alone. Although this was also true for those with dementia and either diabetes or VI, it was not of the same magnitude (see *Appendix 5*).

Unpaid care was common, with over two-thirds of people with dementia alone reporting use of informal help from family and friends. Use of unpaid care was even higher for individuals with dementia and one of the target health conditions, with around eight out of 10 people reporting informal help (see *Figure 7*).

Dementia and comorbidity compared with comorbidity alone

When comparing those with dementia and a target health condition with those with just the health condition, hospital use mostly does not change (see *Appendix 5*). The only case in which there is a difference is for those with dementia and stroke, with use of inpatient services being higher than for those with stroke alone. The use of a home care assistant and a day centre in the previous 4 weeks was higher for those with dementia and the target health condition than for those with the target health condition alone. Of all of the day-to-day services, the use of a care worker was higher for those with dementia and a target health condition than for those with the target health condition alone. Unpaid care was also used more by those with dementia and any of the target health conditions than by those with the health condition alone. However, caution should be exercised when interpreting these results as the estimates have broad CIs because of instability introduced by having a small reference group (the target health condition).

Cognitive Functioning and Ageing Studies I and II comparison analysis

Prevalence

Box 2 shows the key messages relating to prevalence.

The CFAS I analysis was conducted using the 10-year follow-up wave only as the questions on service use were introduced only at this point. Even with the adjustments of the analysis using weights there was still some uncertainty in the estimates because of the low number of people who had the target comorbidities. This also meant that it was not possible to formally test the difference in service use between CFAS I and CFAS II.

BOX 2 Key messages

Between CFAS I baseline and CFAS II baseline:

- the prevalence of diabetes more than doubled
- the prevalence of dementia reduced
- the prevalence of stroke and VI remained the same.

The overall prevalence of the health conditions considered is shown in *Table 6* for those aged ≥ 75 years. Two time points are given for CFAS I: the baseline assessment, which is more directly comparable to the CFAS II baseline assessment, and the 10-year follow-up wave in which service use was measured. Consistent with the main findings from CFAS II,[164] the prevalence of dementia reduced slightly between the CFAS I baseline and the CFAS II baseline assessments. Over the same period the prevalence of stroke and VI remained similar. In contrast, the prevalence of diabetes more than doubled between CFAS I baseline and CFAS II baseline, with CIs that did not overlap. Comparing the CFAS I 10-year follow-up estimates with the CFAS I baseline estimates, the prevalence of dementia and VI decreased. This is likely to be the result of a survivor effect: those with these conditions may have been less likely to survive to the 10-year assessment.

Table 7 gives the prevalence of each of the target health conditions for individuals with and without dementia separately. The likelihood of having one of the health conditions was generally higher for people with dementia across all three time points. The difference in prevalence between those with and those without dementia was smaller in CFAS II and, for VI, there was no difference in prevalence between those with and those without dementia. The prevalence of having at least one of the target conditions was higher in those with dementia than in those without dementia at CFAS I baseline; however, at baseline in CFAS II the prevalence of having at least one target condition was the same in those with and those without dementia.

Service use

Overall service use

Box 3 shows the key messages relating to overall service use.

Figure 8 gives the overall grouped service use for individuals with dementia and one of the target health conditions. Additional details of differences in service use between CFAS I and CFAS II comparing dementia alone with dementia plus a target condition are provided in *Appendix 5*. One of the limitations was that hospital use data were collected for a different time period from that for day patient or outpatient service use data. For example, for day patient and outpatient services participants were asked if they had used them in the previous few months but for inpatient services participants were asked if they had been admitted in the last year. However, it is clear that hospital use increased between CFAS I and CFAS II for those with dementia alone and for those with dementia and stroke.

TABLE 6 Prevalence of dementia and the target comorbidities in CFAS I and CFAS II in those aged ≥ 75 years living in the community

	CFAS I baseline (1991–3)			CFAS I 10-year follow-up wave (2001–3)			CFAS II baseline (2008–11)		
Health condition	*n*	Weighted prevalence (%)	95% CI (%)	*n*	Weighted prevalence (%)	95% CI (%)	*n*	Weighted prevalence (%)	95% CI (%)
Dementia	165	9.9	7.7 to 12.7	83	6.4	3.9 to 10.3	277	8.5	7.5 to 9.6
Stroke	333	9.4	8.5 to 10.4	160	9.7	7.6 to 12.4	377	10.4	9.4 to 11.4
Diabetes	240	6.8	6.0 to 7.6	152	8.1	6.3 to 10.4	540	14.5	13.3 to 15.7
VI	662	18.9	17.7 to 20.3	178	12.5	9.3 to 16.5	602	17.3	16.0 to 18.6
Target comorbidities	1059	30.1	28.6 to 31.7	416	26.3	22.3 to 30.6	1294	34.5	33.0 to 36.1

TABLE 7 Prevalence of target comorbidities in those aged ≥ 75 years with and without dementia and living in the community

Health condition	Dementia			No dementia		
	n	Weighted prevalence (%)	95% CI (%)	*n*	Weighted prevalence (%)	95% CI (%)
CFAS I baseline						
Stroke	38	22.8	14.2 to 34.6	61	9.4	6.6 to 13.3
Diabetes	12	8.1	4.3 to 14.6	33	6.2	3.8 to 10.1
VI	46	24.3	17.2 to 33.3	126	20.9	16.3 to 26.4
Target comorbidities	77	44.5	33.2 to 56.4	186	31.1	25.7 to 37.2
CFAS I 10-year follow-up wave						
Stroke	17	22.6	14.0 to 34.4	143	9.7	8.3 to 11.4
Diabetes	13	15.6	6.6 to 34.8	139	8.6	7.3 to 10.1
VI	19	21.7	13.5 to 32.9	159	11.4	9.7 to 13.2
Target comorbidities	41	47.6	36.5 to 58.8	375	25.4	23.2 to 27.7
CFAS II baseline						
Stroke	47	17.9	13.3 to 23.8	330	9.7	8.8 to 10.8
Diabetes	42	16.2	11.8 to 21.9	498	14.3	13.2 to 15.6
VI	39	16.7	12.1 to 22.6	563	17.3	16.0 to 18.7
Target comorbidities	100	35.7	29.7 to 42.1	1194	35.1	33.5 to 36.8

BOX 3 Key messages

- Hospital service use has increased in the last decade for those with dementia alone and those with dementia and stroke.
- Use of unpaid care has increased from CFAS I to CFAS II for those with dementia and either diabetes or VI.

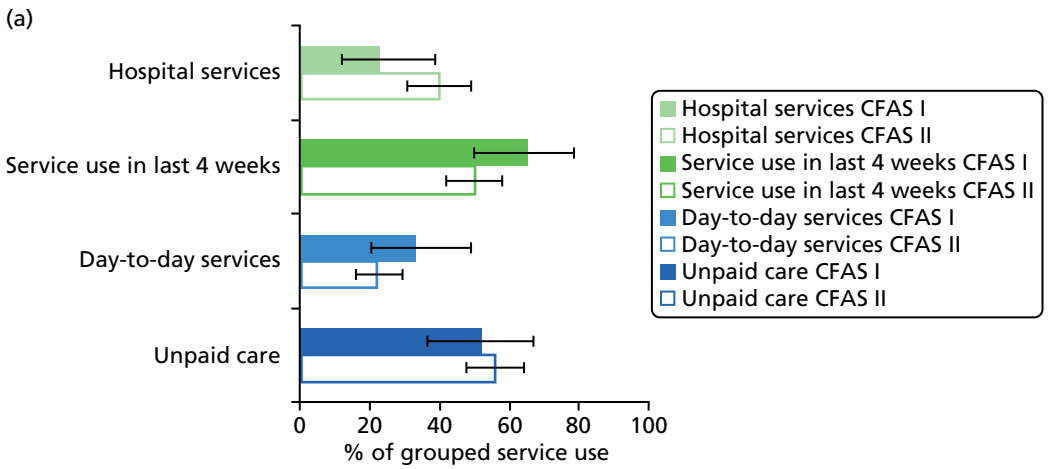

FIGURE 8 Percentage of grouped service use in CFAS I and CFAS II with 95% CIs by those with dementia alone and dementia with each of the target comorbidities. (a) Dementia and no target comorbidity; (b) dementia and stroke; (c) dementia and diabetes; and (d) dementia and VI. (*continued*)

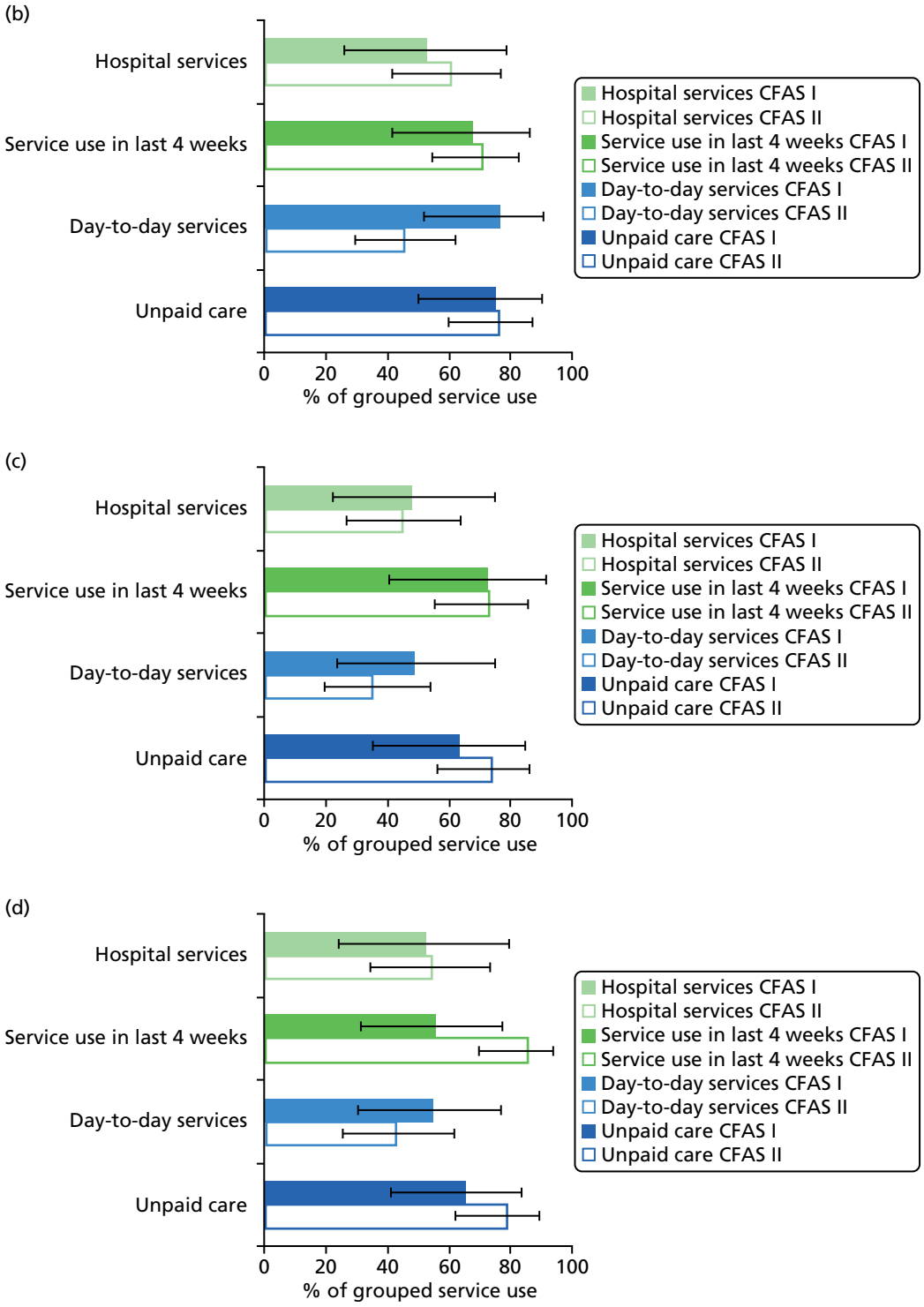

FIGURE 8 Percentage of grouped service use in CFAS I and CFAS II with 95% CIs by those with dementia alone and dementia with each of the target comorbidities. (a) Dementia and no target comorbidity; (b) dementia and stroke; (c) dementia and diabetes; and (d) dementia and VI.

Although hospital service use increased for those with only dementia, the use of day-to-day services and service use in the 4 weeks before interview decreased slightly between CFAS I and CFAS II. Day-to-day service use decreased between CFAS I and CFAS II for all those with dementia and a target condition. Apart from day-to-day service use, those with dementia and stroke had similar service use in CFAS I and CFAS II. This was also the case for those with dementia and diabetes, although there was a slight increase in the use of unpaid care in CFAS II. More change was seen for those with dementia and VI: there was an increase in the use of unpaid care and services in the 4 weeks before interview between CFAS I and CFAS II as well as the decrease in day-to-day service use. Unfortunately, because of non-response this could not be tested formally.

Across all target conditions in CFAS I and CFAS II there was an increased use of unpaid care compared with those having dementia alone.

Separate service use

Box 4 shows the key messages relating to separate service use.

More detailed results on separate services are provided in *Figure 9*. For those with dementia but none of the target health conditions the overall increase in hospital use resulted from an increase in the use of all hospital services but mainly from an increase in day patient and outpatient admissions. The large increase in day patient service use was also present for those with dementia and stroke. Although hospital service use overall increased for people with dementia and stroke, reductions in inpatient and outpatient admissions were observed between CFAS I and II. These decreases were also observed in those with dementia and VI but not in those with dementia and diabetes.

For people with dementia and without any of the target conditions, decreases in service use in the 4 weeks before interview were mainly driven by decreases in chiropodist and social worker use. Increases in day centre use were mirrored in people with dementia and either stroke or VI and there was also an increase in the use of nursing services by those with dementia and stroke. For people with dementia and VI, the overall increase in service use in the 4 weeks before interview was mainly driven by an increase in chiropodist use and GP visits, as well as greater use of day centres. A reduction in the use of meals on wheels was observed across all groups.

Differences in the proportion of people using care workers, paid help or home help on a day-to-day basis accounted for the majority of the change in overall use of day-to-day services across groups. For people with dementia and no target condition, reductions in the use of daily care workers and home help accounted for the majority of the reduction in day-to-day services. Decreases in the use of meals on wheels and care workers accounted for the overall decrease in use of day-to-day services seen for people with dementia and either stroke or VI.

BOX 4 Key messages

- There was an increase in the use of unpaid care for those with dementia and either diabetes or VI.
- Decreases in the use of day-to-day services mainly stem from decreases in the use of paid help and meals on wheels.

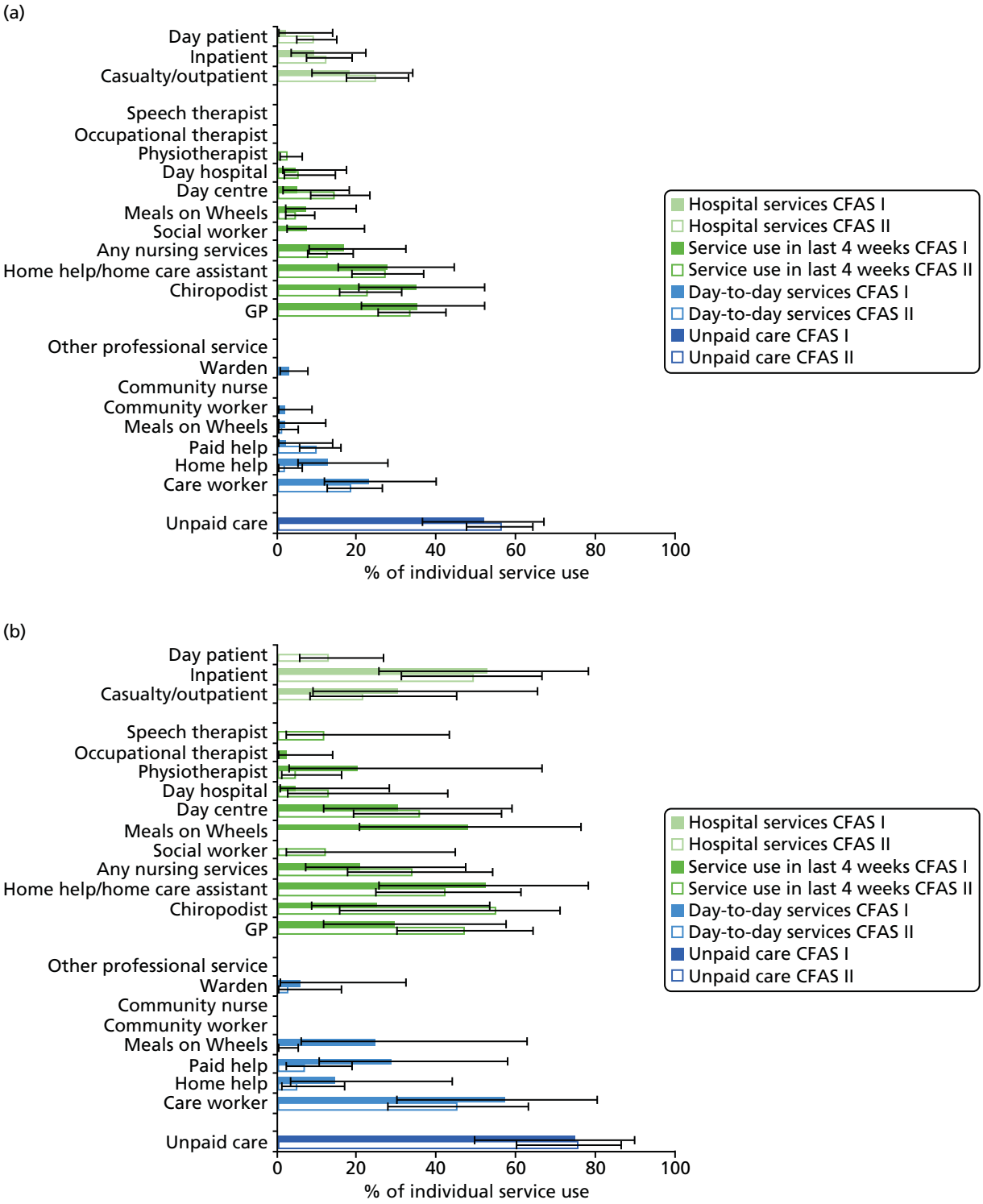

FIGURE 9 Percentage of individual service use in CFAS I and CFAS II with 95% CIs by those with dementia alone and dementia with each of the target comorbidities. (a) Dementia and no target comorbidity; (b) dementia and stroke; (c) dementia and diabetes; and (d) dementia and VI. (*continued*)

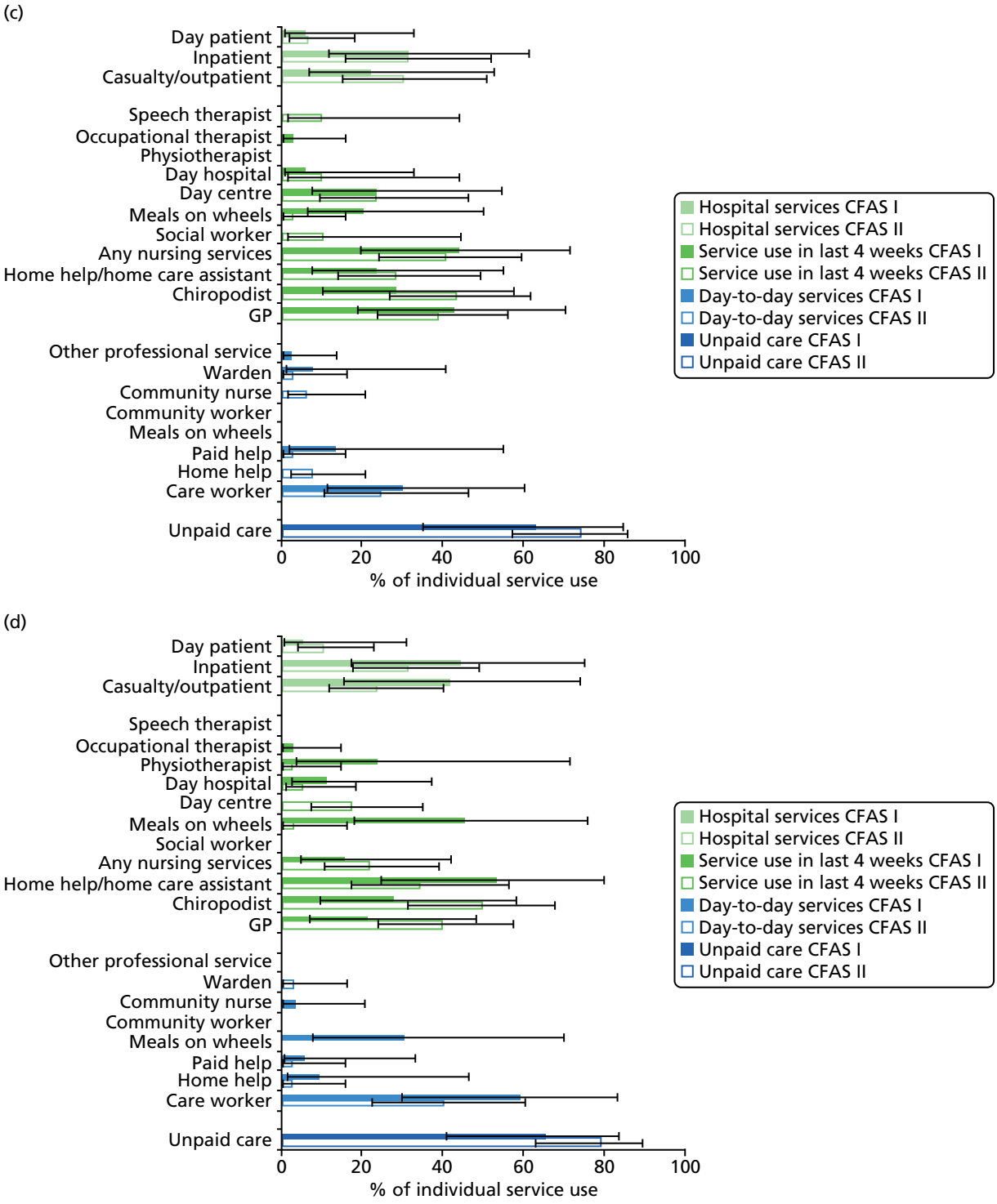

FIGURE 9 Percentage of individual service use in CFAS I and CFAS II with 95% CIs by those with dementia alone and dementia with each of the target comorbidities. (a) Dementia and no target comorbidity; (b) dementia and stroke; (c) dementia and diabetes; and (d) dementia and VI.

Separate services within each condition

Although overall hospital service use remained similar in CFAS I and CFAS II for those with dementia and stroke, there was a decrease in inpatient and outpatient admissions, which was balanced out by an increase in day patient admissions. Between CFAS I and CFAS II those with dementia and stroke used more speech therapists, occupational therapists and social workers, whereas use was low in CFAS I. For this group, there was also an increase in the use of day hospitals and day centres, GPs, chiropodists and nursing services. There was a decrease in the use of physiotherapists, meals on wheels and home help by those with dementia and stroke during this time. The use of day-to-day services decreased for those with dementia and stroke. This was mainly because of a reduction in the use of care workers, home help, paid help and meals on wheels. The use of unpaid care remained similar between CFAS I and CFAS II.

For those with dementia and diabetes there was only a slight increase in the use of outpatient services between CFAS I and CFAS II. Overall, the use of services in the 4 weeks before interview was similar between CFAS I and CFAS II but there were increases in the use of speech therapists, social workers and chiropodists, which were mainly offset by the decrease in the use of meals on wheels. The decrease in day-to-day service use seen in those with dementia and diabetes was the result of a decrease in the use of care workers, wardens and paid help, although increases were seen in the use of community nurses and home help. The use of unpaid care increased substantially between CFAS I and CFAS II for those with dementia and diabetes.

All service use apart from day-to-day service use increased between CFAS I and CFAS II for individuals with dementia and VI. For hospital service use this resulted from an increase in day patient admissions although decreases were also seen in inpatient and outpatient admissions. There was a decrease in the use of physiotherapists, meals on wheels and home help in the 4 weeks before the interview between CFAS I and CFAS II but large increases in visits to chiropodists, GPs and day centres. For day-to-day service use, all service use decreased between CFAS I and CFAS II apart from use of wardens and community nurses. The use of unpaid care increased between CFAS I and CFAS II.

Conclusions

Cognitive Functioning and Ageing Studies II analysis

The CFAS II-only analysis aimed to determine differences in service use between those with dementia and a target health condition and those with either dementia alone or the target health condition alone. The use of unpaid care from family or friends was considerably greater for those with dementia and any one of the target health conditions than for those having the health condition alone. Home care assistants, day centres and care workers were also all used more by those with dementia and a target health condition than by those with the health condition alone. Compared with those with dementia alone, those with dementia and a target health condition visited inpatient hospital services more.

Cognitive Functioning and Ageing Studies I and II comparison analysis

A comparison of service use between CFAS I and CFAS II indicates that use of some services has changed substantially. Over the past decade there have been large increases in the use of unpaid care by some of those with dementia and a target comorbidity whereas a decrease has been seen in the use of day-to-day services, mainly stemming from decreases in the use of paid help and Meals on Wheels.

Chapter 6 Findings from the interviews and focus groups

Characteristics of participants

We interviewed 28 PLWD and comorbidity and 33 family carers. Six PLWD and six carers were interviewed individually ($n = 12$), two interviews were carried out with pairs of family carers (sons/daughters of patient) ($n = 4$) and one interview was carried out with a PLWD and two carers ($n = 3$), but the majority of interviews ($n = 21$) were with patient–carer dyads ($n = 42$). We conducted five focus groups ($n = 29$) and carried out telephone and face-to-face interviews with a further 27 HCPs from a range of different specialities working in primary and secondary care. Further details of the participants are provided in the following sections.

People living with dementia and comorbidity and family carers

People with dementia and their family carers were recruited to the study through GP practices, dementia registers, memory clinics and voluntary organisations (Alzheimer's Society, Thomas Pocklington Trust, Stroke Association) in the north-east and south-east of England. The numbers of completed interviews by region and comorbidity are provided in *Table 8*. The numbers of PLWD and carers by comorbidity and region are presented in *Table 9*.

In total, 64% of the PLWD were male and 72% were white. The age range of the PLWD was 59–94 years (median 82.5 years). The most common form of dementia was Alzheimer's disease (56%), followed by mixed dementia (19%) and vascular dementia (17%). A total of 8% of participants had Parkinson's disease with dementia. The majority of PLWD lived with a carer (78%), either a spouse (64%) or an adult child (14%). Carers were aged between 46 and 90 years (median 65 years). The types of comorbidity present are provided in *Figure 10*, which shows that > 50% of patients had diabetes, 45% had VI and 28% had had a stroke.

TABLE 8 Numbers of completed interviews by region and comorbidity

Region	Diabetes	Diabetes/VI	Stroke	VI	Diabetes/stroke/VI	Total
South-east	7	5	7	7	1	27
North-east	5	1	2	1	0	9
Total	12	6	9	8	1	36

TABLE 9 Numbers of PLWD and carers recruited by region and comorbidity

	Diabetes		Diabetes/VI		Stroke		VI		Diabetes/stroke/VI		Total number of participants	
Region	PLWD	Carer	PLWD	Carer	PLWD	Carer	PLWD	Carer	PLWD	Carer	PLWD	Carer
South-east	4	8	4	5	5	5	5	6	1	1	19	25
North-east	5	3	1	1	2	3	1	1	0	0	9	8
Total number of interviews	12		6		9		8		1		61	

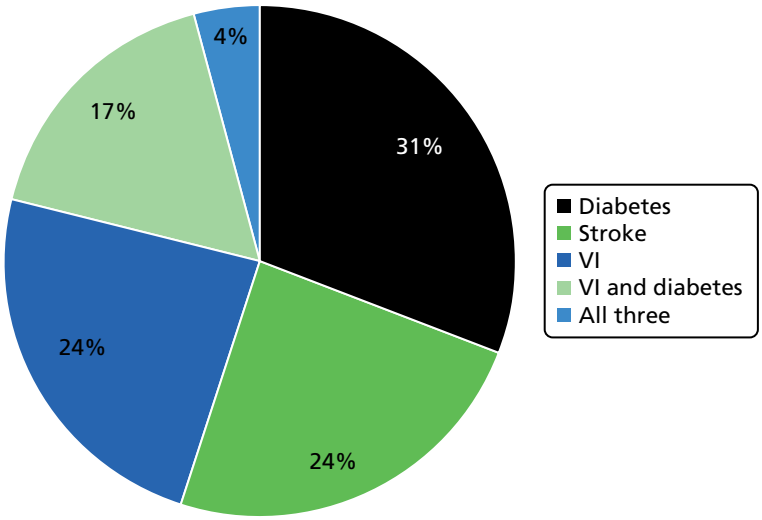

FIGURE 10 Types of comorbidity.

Health-care professionals

We recruited 56 HCPs, comprising 10 GPs, 18 nurses (specialist and general), 12 consultants/senior clinicians specialising in stroke, diabetes and VI, eight therapists, two managers, one old-age psychiatrist, one health-care assistant and four vision specialists (two orthoptists, one optometrist, one intravitreal co-ordinator). *Table 10* provides details of the numbers of interviews by region and specialty and *Table 11* provides details of the focus groups by region and specialty.

TABLE 10 Numbers of interviews with HCPs by region and specialty

Region	Primary care	Diabetes	Stroke	VI	Dementia	Total number of interviews
South-east/London	5 GPs[a]	2 nurses, 1 GP – diabetes lead for CCG	1 physiotherapist, 1 manager CCG, 1 manager social services	1 consultant, 1 clinician/ researcher	1 consultant	14
North-east	4 GPs,[b] 1 practice nurse	2 nurses, 1 consultant	2 nurses, 2 consultants	0	1 CPN (specialising in dementia)	12 (13 HCPs)
Total	10	6	7	2	2	26 (27 HCPs)

CCG, clinical commissioning group; CPN, community psychiatric nurse.
a Included one CCG commissioner.
b Included two CCG commissioners.

TABLE 11 Focus groups with HCPs by region and comorbidity

Region	Specialism	Setting	Roles of HCPs	Number of HCPs
Midlands	Stroke	Secondary care	3 stroke consultants, 1 rehabilitation lead	4
South-east	Stroke	Community	5 specialist neurological physiotherapists, 1 occupational therapist	6
London	Diabetes	Community	4 specialist diabetes nurse consultants	4
South-east	Diabetes	Secondary care	3 consultants, 5 diabetes specialist nurses	8
East of England	VI	Secondary care	1 consultant ophthalmologist, 2 orthoptists, 1 specialist optometrist, 1 staff nurse ophthalmology, 1 senior health-care assistant specialising in VI, 1 intravitreal co-ordinator	7
Total				29

Results of the thematic analysis

Qualitative data were analysed using a framework informed by theories of continuity of care and access to care (see *Chapter 2* for further details). Our two overarching themes were negotiating continuity of care and negotiating access to care. The themes and subthemes are summarised in *Figure 11* and are detailed in the following sections; quotations are provided to illustrate the themes.

Theme 1: negotiating continuity of care

Relationship continuity

People living with dementia and their family carers value relationship continuity

A common thread in the interviews with PLWD and their carers was that they valued a continuous relationship with HCPs and health-care teams who knew their medical history and were aware of their health-care needs. Successful interactions with HCPs were usually associated with positive personality characteristics such as friendliness, warmth and being treated with consideration and respect. Good communication skills, taking time to explain things and including PLWD and their carers in decisions were valued. There were examples in which a rapport was developed with a HCP because he or she had taken the time to get to know the patient:

> *and he struck up a really warm relationship with this doctor and now he really likes going there and I expect they have the same conversation every time he goes.*
>
> *Carer VI 3, south-east*

Likewise, less successful interactions were often attributed to HCPs' negative personality characteristics and poor communication skills. Examples given were that the HCP was stern, abrupt and rude and spoke with no eye contact or in a patronising manner:

> *he was quite rude to us and we weren't happy, he sort of didn't look up, he was looking down.*
>
> *Carer diabetes/VI 4, south-east*

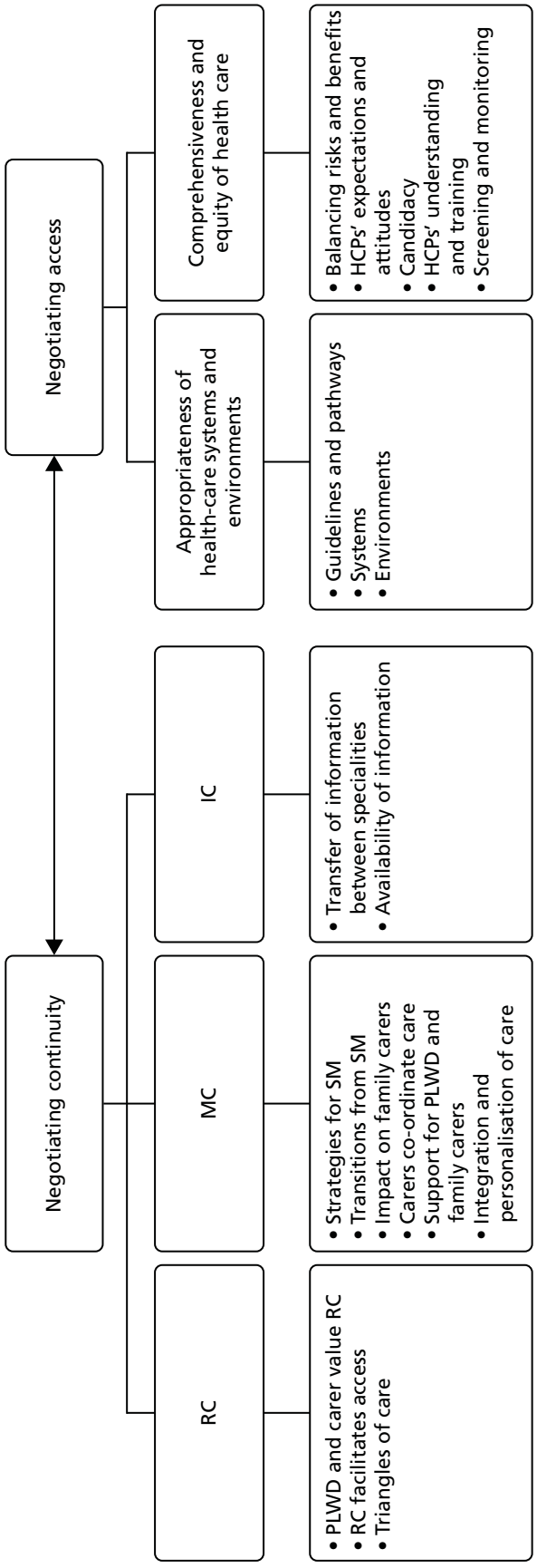

FIGURE 11 Themes and subthemes. IC, informational continuity; MC, management continuity; RC, relationship continuity, SM, self management.

For many of our participants their comorbid health condition predated the diagnosis of dementia. Despite this, participants gave very few examples of when a diagnosis of dementia was discussed in relation to its implications for and impact on their overall health and the management of any existing conditions. Moreover, patients sometimes felt that the diagnosis of dementia had been delivered in an insensitive way. This carer talks of being 'catapulted into despair':

> *. . . in fact a nurse, I think looking back she was very out of order to say this, I think she said 'I think it's small vessel disease', and I said 'how do you treat that?', and she said 'there's no treatment' . . . I mean this nurse really catapulted me into despair.*
>
> *Carer stroke 7, south-east*

Continuity with social carers was also very important for PLWD and their family carers. Previously well-documented problems associated with paid carers' erratic schedules and multiple people visiting the same person posed particular challenges for PLWD. It threatened their ability to manage their medication (especially a problem for people with diabetes) and stay in their own home. One carer gave an example of how she had negotiated with an agency to limit the number of carers visiting to a maximum of three, a number that accommodated times of staff leave and sickness:

> *I said to them, 'We cannot have different carers coming in, we cannot have different,' so they've said they'll keep it to three which is fair enough because you have sickness.*
>
> *Carer diabetes 7, south-east*

Relationship continuity facilitates access to care

Relationship continuity with both the clinician and the practice management or support staff meant that additional administrative practices could be applied to address the potential for missed appointments because of memory loss. When HCPs knew patients and were aware that they had dementia, they were more likely to remind them of upcoming appointments, give longer appointments and make allowances when they missed appointments. However, we found no examples of when a dementia diagnosis would automatically trigger the kind of practice described by this GP:

> *In fact when I know that I've got one of my patients with dementia booked in I will ask, I will send an email in advance to the administrator, to the receptionist to sort of call them on the day to remind them.*
>
> *GP 2, London*

In addition, relationship continuity could facilitate assessment and treatment, for example making it easier for VI specialists to conduct and interpret tests, although, as the following quote demonstrates, such approaches were reliant on individual clinician's knowledge of the patient. How this knowledge of the person could be shared more widely was less clear.

> *I get some dementia patients come to the AMD clinic and usually with a carer of some description, and then we have the difficulty of assessing their vision because of them not being able to verbalise what they're seeing but usually those patients I've got to know and I can tell if they're making a reasonable assessment or whether they've just switched off and on the whole I can tell, you know, that they're understanding and I can understand what they're seeing.*
>
> *Staff nurse, VI focus group, East of England*

Many PLWD and their carers reported positive continuous relationships with their GP and recognised the role that GPs played in overseeing and co-ordinating their care and facilitating access to care. There were multiple examples of GPs helping to organise social care for PLWD, following up with memory clinics, contacting pharmacies for prescriptions, chasing referrals, contacting transport providers and providing PLWD with signposting and information. This would suggest that clinicians in regular contact with PLWD

were aware of the compensatory and anticipatory care that these patients needed when visiting other services. However, this was discretionary, required individuals to be engaged and proactive and did not necessarily translate into systems of care.

Triangles of care

In many cases interactions involved a triad of the PLWD, the family carer and the HCP. HCPs in our study were aware of the role of family carers in co-ordinating and managing their relative's health care. In the focus group with VI specialists participants said that they actively encouraged family carers to accompany the PLWD to the eye clinic as they could provide important information and help the PLWD feel at ease during eye tests:

> *Well really important, really important, and I think they need to be involved in sort of every step of the way.*
>
> *Ophthalmologist, VI focus group, East of England (speaking about involving family carers)*

Stroke consultants reported that they involved family carers in decisions about whether to thrombolyse a PLWD. HCPs' awareness of the importance of involving family carers was reflected in some of the accounts given by family carers:

> *when I rang to make the appointment I said to them, 'My dad's got Alzheimer's disease but he won't acknowledge that, but he does need extra time and I'd like to come with him because he may need my support, emotional support but he may also need me to help interpret some of the questions that he's being asked', and they were great, they gave him a double appointment, so he'd got twice as long as he would normally have, and they were quite happy for me to go.*
>
> *Carer VI 3, south-east*

However, the interviews with PLWD and their carers provided a number of examples in which carers felt undervalued or excluded from decision-making about their relative's care. For example, there were several accounts in which carers felt ignored by HCPs when they struggled to get treatment for their relative:

> *And in fact I can remember it took at least two, if not three phone calls to the practice nurse, because at first you came off the phone . . . That's right, because we'd been telling them there's a problem, put it in writing, we thought we'd got the message across didn't we?*
>
> *Carer diabetes 4, south-east*

> *I did get a bit annoyed two years ago because all they do is we bring him in, they check the pressures at the back of his eye and then they say to him, 'Can you read that card?', they put a few drops in, we see someone and we come home, and that's been happening for five years. Now this year I asked for a second opinion and he's never seen the glaucoma people.*
>
> *Carer diabetes/VI 4, south-east*

In one account, a district nurse gave a patient with dementia and diabetes a new blood testing kit without giving the family carers information about how to use it:

> *Do you remember that mum, you know your method for testing your blood that you'd used for years, last Easter the nurse came on Maundy Thursday, the day before Easter and she gave you a new machine to do it . . . And you could not fathom it at all . . . No, no, none of us could, could we? It was chaos.*
>
> *Carer diabetes 4, south-east*

Sometimes PLWD would also feel excluded and ignored when HCPs communicated only with their family carer:

> *Yeah, but I mean really when I sit in on that with Dr [consultant], really I could almost be invisible at some times because he doesn't concentrate on me at all, he's always concentrating on you.*
>
> *PLWD diabetes/VI 6, north-east*

An example of good relationship continuity with a GP and how this can facilitate access to services can be seen in the vignette in *Box 5*. This describes a particular case from the data and illustrates the complex health needs of some people with dementia.

Management continuity

Strategies for self-management of comorbidities

Some PLWD were still able to self-manage their care, including booking their own appointments, attending appointments alone and remembering to take medication. PLWD developed a variety of strategies to facilitate self-management of conditions such as diabetes and glaucoma. This included taking tablets or administering eye drops at the same time each day or putting medication in a particular place once it had been taken. One man with dementia and glaucoma described how he kept his eye drops in one place on a chest of drawers and, once he had administered them, he would move the bottle to the other side of the drawers. This would indicate to him that he had used the eye drops even though he might not remember doing so:

> *His plan is that he has them on this side in the morning, and he puts them over there, and then in the evening he puts them back on that side.*
>
> *Carer VI 1, south-east*

Transitions from self-management to dependency

As their dementia got worse, the ability of PLWD to self-manage their condition declined and management moved from the PLWD to the carer. This transition was often a gradual process, with carers initially noticing small changes in their relative's ability to manage that could be dealt with by adopting strategies to facilitate self-management, for example using memory aids, diaries and dosette boxes. However, over time, these strategies ceased to be effective:

> *gradually I took over the medication, each step was really painful, you know 'cos he always used, he was on by the time when he started sort of losing grip on things he was on a lot of medication, six or eight different pills a day and he would line them up and take them one at a time and so on, and then I started putting them in dosette boxes and then he started not remembering to take them and then he would take them at random so gradually I took over the whole thing and I mean there were a lot of tears and agony.*
>
> *Carer stroke 7, south-east*

BOX 5 The importance of relationship continuity for someone with dementia and multimorbidity

Mr A is a 62-year-old man with vascular dementia and multiple conditions, including all three of our target comorbidities. He believes that one condition has led to another, that is, an operation on his pancreas caused his diabetes, which in turn caused his eye condition and his stroke. He has had numerous surgical procedures and has a complex medication regime that he manages by having a strict routine. His dependency on his wife for managing his health care and his conditions has increased as his dementia has become worse.

The patient has a positive relationship with his GP, who sees him every month for blood tests and to review his conditions. The GP will find time to see him, even at 7 a.m. before surgery starts. His stroke was diagnosed after his wife noticed something was wrong and encouraged him to see his GP. His GP sent him for a computed tomography scan and he was then seen at the stroke clinic. The patient was pleased with the quick response and said the stroke consultants were very good at explaining things to him. As a result of his stroke he has difficulties speaking. He devises strategies to cope with this but says that the effects of the stroke have caused him to be depressed. The stroke has affected his sense of taste and his appetite and he is losing weight. This has implications for his diabetes. He was referred to a physiotherapist for rehabilitation but finds the exercises too difficult and demanding for him.

we had a timer at the beginning and it bleeped when he should take a tablet, well he would go and turn the bleeper off and forget to take the tablet . . .

Carer VI 6, south-east

In some instances people with diabetes had successfully managed their condition for many years but had began to forget to take their medication or to lose the ability to control their diet. Carers of people with dementia and diabetes reported how it became difficult to regulate blood sugar levels because their relative often forgot to eat and drink, ate too much or ate the wrong kind of foods. There were safety concerns for people in this period of transition, with accounts of people forgetting to take medication or taking too many tablets or too much insulin:

Another risk that was highlighted to me recently was a patient in this circumstance who was previously self-managing, district nurses had to take over, but the insulin has to stay in-house and the nurses don't carry it around, so this patient was, it transpired this patient was given her own insulin and the district nurses were coming in after and administering again, it took a while to establish that.

Diabetes consultant, diabetes focus group, south-east

An example of the transition from self-management to dependency for a woman with diabetes and dementia is provided in *Figure 12*. As a result of her dementia, this patient gradually became unable to manage her diabetes. This resulted in a hypoglycaemic attack and hospitalisation, after which she deteriorated and could no longer live alone.

Impact of managing dementia and comorbidity on family carers

Many family carers, in particular spouses, had their own health problems, which made it difficult for them to help manage their relative's conditions. Other carers, such as adult children, sometimes lived a distance away or had work and family commitments which meant that they found it difficult to take on

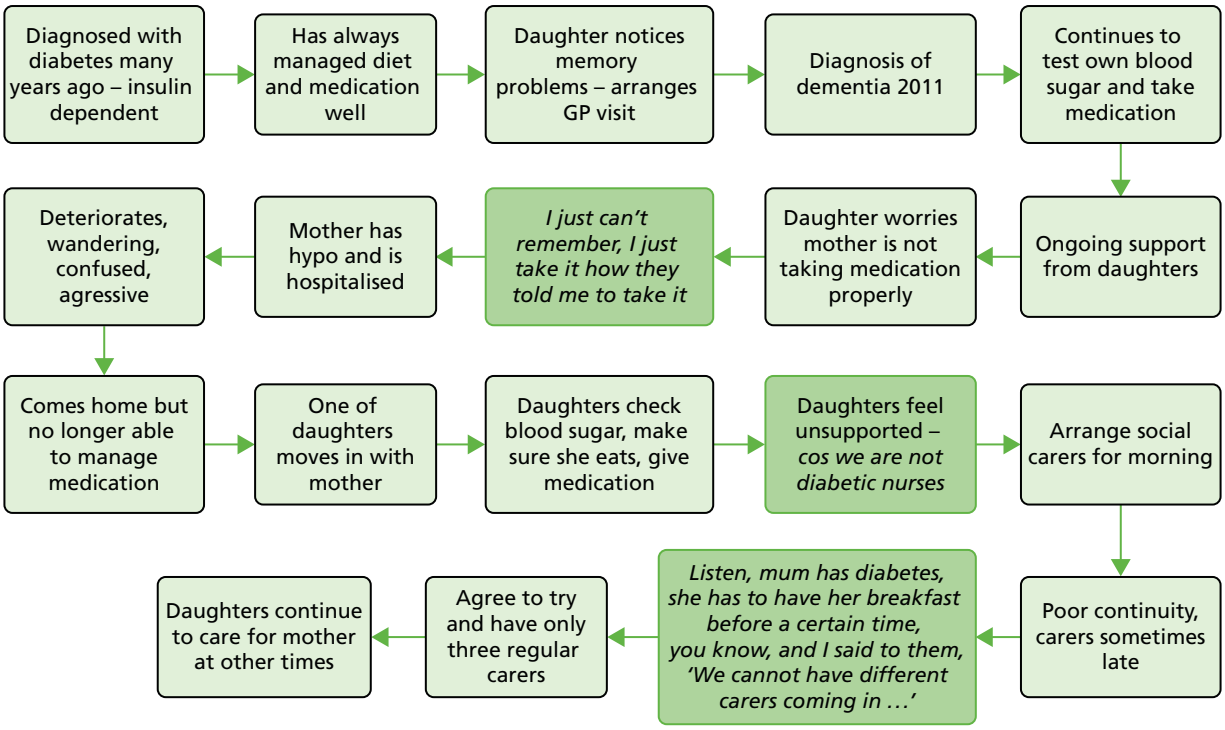

FIGURE 12 Transition from self-management to dependency.

responsibility for day-to-day care. Although many family carers have to care at a distance this is particularly problematic for carers of PLWD as it is difficult for them to offer support or to monitor adherence to medication over the telephone:

> *I know yesterday you had a bit of a problem because you thought, when I phoned you up in mid-morning you thought that the lady hadn't been to give you your medications and your Cornflakes but in fact she had, hadn't she?*
>
> *She had, yeah.*
>
> *So mum ended up having two breakfasts yesterday.*
>
> *Carer and PLWD diabetes 4, south-east*

For carers of people with dementia and diabetes, coping with the administration of insulin or testing blood sugar could be particularly challenging, because they felt that they lacked the necessary skills, because their relative became distressed or because they did not feel comfortable with the task:

> *And I'm waiting for someone to realise [laughs] 'cos we're not diabetic nurses.*
>
> *Carer diabetes 7, south-east*
>
> *'now mam, you've got to do this', I said 'look I'm not a nurse'.*
>
> *Carer diabetes 8, north-east*
>
> *He doesn't want it, he tries to refuse it and it is all horrible because it's needles all the time and it hurts, you know, he doesn't like it and I have to take bloods, and I say, 'I'm sorry dad, you have to have it, your health will be worse, you'll deteriorate even quicker', he doesn't care, he doesn't want to be on anything.*
>
> *Carer diabetes/VI 4, south-east*
>
> *the minute you start asking them [referring to family carers] to do something technical or in their eyes complicated, such as pricking their finger, doing a blood sugar test or giving insulin, they kind of go, 'No, I can't do that', and they'd be capable of doing it because we can teach them and support them and so on but there's a barrier that they can't get beyond where, no that's beyond what I'm prepared to do, happy to do, comfortable to do.*
>
> *Diabetes consultant, diabetes focus group, south-east*

It was clear that there were emotional as well as practical and physical challenges for family carers as their role changed from spouse or child to carer:

> *Oh it was, she was like [laughs], . . ., you know, tantrums, you know, 'I'm not doing that', you know, flat refused [laughs] . . . Oh yeah, honestly, it's quite funny, I mean sometimes you sort of think it definitely has been a role reversal, you know, you become the parent.*
>
> *Carer stroke 4, south-east*

Family carers co-ordinate care and navigate health-care systems

Family carers clearly play a significant role in co-ordinating their relative's care and navigating health-care systems, for example managing multiple appointments, organising transport and keeping records of appointments, test results and medication:

> *And now I go with him for all his appointments . . . I have got a notebook there which I use to note everything, you know, when it started [sound of paper rustling] for myself, for my own, you know . . . I used to record everything, 'seen by so and so, what prescribe and when to be seen again' and all these things.*
>
> *Carer diabetes/VI 2, south-east*

Carers reported that they often had to chase up results or referrals and 'battle' to get appointments or access to treatments and tests. The following quote illustrates the frustration of a carer whose father's electrocardiogram results had not been sent to the memory clinic:

> *I have to chase everything up in the surgery . . . the week before last for them to actually get the ECG [electrocardiogram] results because I had to go and pick them up and physically take them there myself.*
>
> *Carer stroke 2, south-east*

Although such experiences are not unique to the carers of PLWD, they may be more acute for them as evidence suggests that PLWD are a particularly vulnerable group who may have poorer access to services than people without dementia. They are also a group who generally lack the ability to co-ordinate their own care and are reliant on family carers to negotiate systems on their behalf. Moreover, HCPs' concerns about confidentiality meant that carers sometimes had trouble accessing the information that they needed to manage their relative's care, for example being unable to collect prescriptions or being refused copies of letters or details of hospital appointments. Some carers had proactively managed to add their contact details to health files so that they would receive copies of any letters sent to the PLWD, but this was not carried out routinely. Although a number of carers and PLWD mentioned lasting power of attorney, this was seen as facilitating management of financial affairs rather than health care.

Support for people living with dementia and family carers

Many HCPs recognised the importance of supporting family carers. One local initiative cited by a HCP was a carer-friendly hospital programme piloted on the stroke unit. This included a carer's agreement that was completed on admission by the family carer in conjunction with a member of ward staff:

> *one of the things that ran very successfully in [name] Hospital this year was a carers, the Carer Friendly Hospital, and they piloted it on the stroke unit and I think that's also about making sure that the carers of people who have dementia as well as stroke or who have multiple other comorbidities have the support.*
>
> *HCP stroke CCG 1, south-east*

However, often support for carers was limited and there appeared to be little in the way of formal support for carers managing their relative's diabetes. For example, the daughters of a PLWD with diabetes felt that a telephone call with a diabetic nurse every 2 weeks was not adequate support:

> *I think 'cos remember we're just carers, and I think we have someone professional that comes in to do, especially the insulin at night to actually check to say, 'Well yeah this is okay', you know, I don't think we get anything like that.*
>
> *Carer diabetes 7, south-east*

Informal social networks, such as extended family, friends and church groups, were clearly important to PLWD and their carers. In addition, voluntary organisations such as the Stroke Association, the Alzheimer's Society and Parkinson's UK provided social and practical support to people with dementia and comorbidity. Voluntary groups were able to provide condition-specific information, peer support and guidance about the support available.

One physiotherapist noticed that the Stroke Association was having more impact in supporting patients and carers.:

> *and certainly some of the stroke patients I've been seeing more recently, whatever age, young or elderly, with issues, have had contact from a Stroke Association visitor or phone call, and, oh and some of them are using them more and I think that's very helpful to the spouses and carers 'cos it, as a form of support.*
>
> *Physiotherapist 1, south-east*

the Alzheimer's Society have been fantastic . . . Oh the Alzheimer's Society, . . . that's a godsend that is, absolutely godsend, yeah.

Carer stroke 4, south-east

Local groups could be a good source of peer support. For example, one PLWD who had been suffering with depression since having a stroke said that he appreciated the peer support he received from attending his local Stroke Association group.

Integration of services

The participants with dementia generally had complex health needs and were often seen by a number of different services and specialties. Carers and PLWD felt that specialists tended to focus on their own area and did not share information with other specialities. As the following quote shows, they did not necessarily see this as a problem but recognised the value of having one professional (in this case the GP) who could look at the 'whole picture':

memory loss, no, they're not interested in that, they're interested in treating the symptoms of diabetes not somebody else's, it's almost like somebody else's problem but I don't mean that hard-heartedly, I mean that we are dealing with this bit, there's nobody, other than my GP looking at the whole picture.

PLWD diabetes/stroke/VI 1, south-east

Health-care professionals from the specialties studied admitted that they had a limited understanding of the needs of PLWD. For example, diabetes specialist nurses said that they were unsure about when to refer someone with cognitive problems:

when you identify somebody who's having a problem with their memory and you're following them up, . . . at what point should they be referred to this sort of agency, you know, what parameters do you use to measure it, you know, all of those things that I can't say really what that is and I don't know if I could say if any of my colleagues do either.

Diabetes specialist nurse, diabetes focus group, London

Several HCPs recognised that the organisation of services around single diseases was a problem for PLWD with complex health needs. The current infrastructure did not support the exchange of information and in particular participants said that poor integration of mental and physical health services, with different information technology systems, made it impossible to share medical records:

And I think that's a key point I was going to make is one of the big stumbling blocks we have is the fact that services or parts of different trusts so the Mental Health Services sit within the [name] Partnership Trust so they don't use the same system as us so we can't share notes, the GPs use a different system again so it makes it very difficult to communicate to even find out what services people are under, you know, if that could be improved, if we could all be on the same system that would be good [laughs].

Physiotherapist, stroke focus group, south-east

There were some examples of successful integrated working, such as community matrons, or a community multidisciplinary team involving a geriatrician, an old-age psychiatrist, elderly care nurse specialists, GPs and a social worker who had regular face-to-face meetings. The presence of a key person or lead clinician to co-ordinate care was consistently identified by different participants as compensating for the known problems and challenges of services defined by single diseases and PLWD's multiple encounters with different professionals:

I think new services like in L1 [London Borough] we have the community matrons have actually been of great help because they are more of care co-ordinators which I think do help these people with comorbidities in the community.

GP 2, London

Personalisation of care

Health-care professionals spoke about the importance of personalising care for PLWD. For example, diabetes specialists said that they would personalise targets for blood sugar control for PLWD:

> *And some of the nursing staff have been working with their community colleagues quite intensively to develop individualised regimes to try and, you know, if they eat half their meal to give this amount of insulin, if they eat all of the meal to give a different amount of insulin, so it's almost like a sliding scale, it's individualised, it's not for every patient but for those who sometimes refuse food it's sometimes really quite a helpful way to prevent them having to keep coming back in with hypos or highs.*
>
> *Diabetes consultant, diabetes focus group, south-east*

Vision impairment HCPs also said that they would simplify medication regimes for PLWD by reducing the number of times that they would need to administer eye drops. Stroke specialists said that stroke rehabilitation regimes needed to be personalised for PLWD and take into account the kinds of activities that they like to do:

> *And you might need to take more of a sort of automaticity approach so just, you know, find out what the patient likes to do, whether they like dancing or just, you know, try and go on the automatic things that aren't too cognitively challenging to try and engage them as much as possible.*
>
> *Physiotherapist, stroke focus group, south-east*

Although HCPs acknowledged the importance of personalised care, it was not clear to what extent this was happening in practice. As this GP observed, there was a common understanding of the importance of having a person-centred approach but they were unsure what the practical application of these ideas looked like:

> *you get the vocabulary established but then people latch onto the vocabulary and not the meaning, 'the holistic care', you know brilliant one, but then what do people mean by it?*
>
> *GP clinical commissioning group 1, Midlands*

There were clear examples in which there was a failure to know the person's story and tailor care accordingly, for example not adjusting stroke rehabilitation for a PLWD who had been a keen walker but who struggled with the rehabilitation exercises he was given:

> *we went three or four times and they said you know, 'these exercises will help you', well exercises are not part of what D does and they didn't really help him, you know, . . . and I mean he just found it ridiculous to be doing these things.*
>
> *Carer stroke 7, south-east*

Information continuity

Transfer of information between specialities

People living with dementia, family carers and HCPs all gave examples of poor information transfer between systems and specialities. Of particular concern was that HCPs specialising in diabetes, stroke and VI were often unaware that someone had a diagnosis of dementia:

> *But obviously anywhere new that we go, like for this colonoscopy and all that sort of thing, I always mention, you know, 'he has dementia quite, quite severe dementia', I think when we went for a blood test for this colonoscopy it wasn't on his notes there, although it was on the original colonoscopy referral sort of thing. So it seems that within the hospital set-up they don't always transfer all relevant information between departments.*
>
> *Carer diabetes 1, south-east*

Diabetes specialists sometimes became aware that someone had dementia only when they realised that they were having problems self-managing their condition or taking on new information. VI specialists reported that they were frequently not made aware that a patient had dementia before they saw him or her in clinic, which made assessments and treatment more difficult.

Family carers were facilitating informational continuity by collating records and actively transferring information between HCPs and different services. Carers and PLWD were frustrated that they often had to repeat the same information to different HCPs:

> *You see one person one time and then you'd have, tell them what they need to know and then you see the next person and they don't know, do they. You have to go all through it.*
>
> *Yeah, you have to start again. But I mean, that actually is a problem with the NHS all the way through, I mean, because it's a kind of, you know, you're not always treated as a whole person, you're treated as individual bits, aren't you.*
>
> *PLWD and Carer VI 7, south-east*

Carers also reported problems with record-keeping, which may be particularly problematic for PLWD who are likely to be unable to provide an accurate medical history to clinicians:

> *but then what happened was it was, we came back here and he didn't have no notes or recollection of my dad seeing that doctor in October.*
>
> *Carer diabetes/VI 4, south-east*

Health-care professionals from all specialities suggested that PLWD could have a hand-held record to take to appointments, similar to the ones carried by people with learning difficulties. It was clear, however, that the interviews were the triggers for these suggestions and that patient-held records had not been developed for PLWD or their carers, as this quote demonstrates:

> *I guess maybe the purple folder I've just mentioned, I've not thought of it before but it's potentially something that can be passed, you know, from one professional to another even if you just write a few words, entry, at least then people know who else is involved with the care and especially if their usual carer isn't about for whatever reason, you know easily who to contact.*
>
> *GP 5, south-east*

However, although hand-held personalised documents such as the 'This is me' passports exist as a way of ensuring that PLWD can share key information about themselves with HCPs [see http://alzheimers.org.uk/thisisme (accessed 7 January 2016)], we found that very few PLWD, carers or HCPs were aware of them. One carer thought that she had been given a 'This is me' passport but said that it wasn't filled in and she didn't use it. One patient mentioned having had a small card that detailed that he had Alzheimer's disease and his next of kin, medication and doctor's details, but he had misplaced it.

Availability of resources/information

There were clearly issues about the timely delivery and availability of information for people with dementia and another health condition. HCPs acknowledged that there is often a lack of support, information and training for people with dementia and diabetes and their carers. One HCP said that diabetes educational programmes vary across different regions and not all programmes are open to carers or PLWD who cannot self-manage:

> *But structured education varies in its availability anyway and the programmes vary and access to the programmes in different areas will vary, so whether they're happy to accept carers or whether it's only open to a person with diabetes and it's therefore not open to somebody who has diabetes and dementia or who can't actually self-care.*
>
> *Diabetes nurse 1, south-east*

There was a suggestion from some HCPs that PLWD would not be considered suitable for some of the educational programmes that were offered for stroke:

> *We also run a huge sub-management programme which does have a module for people who have had strokes as well as two general modules and somebody with dementia we wouldn't invite necessarily to those modules so they themselves would miss out on a huge bit of secondary intervention and advice that they might get otherwise and because we don't invite the carers automatically the carer also doesn't get the secondary intervention advice.*
>
> *Physiotherapist, stroke focus group, south-east*

Some of the problems with relationship, management and informational continuity that have been detailed in the previous sections can be seen in the vignette in *Box 6*, which describes a specific case from an interview with a PLWD and her daughter. In particular, it highlights the transition from self-management to dependency and the problems that this cause for the family carer, who lives at some distance and feels excluded from decision-making about her mother's condition.

BOX 6 The transition from self-management to dependency

Mrs B is a 92-year-old woman with type 1 diabetes and Alzheimer's disease. She lives alone but has the support of her daughter, who lives a long distance away. Her daughter finds it difficult to manage and co-ordinate her mother's health care from a distance.

Mrs B managed her diabetes well for 20 years, testing her bloods and injecting insulin twice a day. The daughter noticed that something was wrong when her mother was no longer able to manage her diabetes, that is, forgetting to eat, eating too much and forgetting medication. The daughter had to 'battle' (two or three telephone calls and a letter) with the GP practice to obtain a diagnosis of dementia for her mother. Mrs B does not always see the same GP and there appears to be poor relationship continuity.

Mrs B is now visited by a district nurse, who checks her bloods but the daughter is concerned that these visits are not regular enough and is worried that her mother's diabetes is not being monitored properly. Recently, her mother has lost a lot of weight and has been taken off insulin. They were not sure if she had received any foot checks for diabetic neuropathy. However, the daughter said that her mother was seen by a private chiropodist and they assumed that she would notify them if there was a problem with her mother's feet.

On a number of occasions changes have been made to Mrs B's medication or care without informing her daughter. For example, one GP made changes to her medication that she was unable to cope with. On another occasion the district nurse issued a new blood testing kit to Mrs B but did not leave written instructions or inform the family. Mrs B was unable to use the kit and the family could not get in touch with the surgery for help as it was closed for 4 days over the Easter break. The daughter feels that she is not included in the decisions about her mother's medical care and would like to be more informed.

The daughter now pays for private carers to visit her mother every morning and evening to give medication.

Theme 2: negotiating access to care

Appropriateness of health-care systems and environments

Appropriateness of guidelines and pathways

The data from the interviews and focus groups suggest that current guidelines and care pathways for diabetes, stroke and VI are often not appropriate for people with dementia and comorbidity:

> *You know, we have clinical pathways for the various specialties, and conditions, but not particularly aimed at patients with memory loss. I guess one could have sort of a subset of, yeah, within various guidelines, but I don't think we have any in that at the moment in ophthalmology.*
>
> *Ophthalmic surgeon, VI focus group, East of England*

> *I think in terms of thinking about stroke pathways, in terms of dementia I think that one of the things is, one of my criticisms if you like of the stroke pathway is it's very much related to the stroke and in relation to looking at comorbidities, not just dementia but a lot of the comorbidities, sometimes perhaps it's not as robust as it could be.*
>
> *Stroke clinical commissioning group 1, south-east*

Health-care professionals also said that dementia pathways do not take into account those patients with comorbidities such as diabetes or VI:

> *I think that's my next step is to try to raise a bit more of an awareness of vision within the dementia pathway.*
>
> *Ophthalmologist 1, London*

Some of the problems associated with current stroke pathways are illustrated in *Figure 13*. Many stroke pathways are geared to early discharge. Although reducing the amount of time that a PLWD spends in hospital may be a good thing, they may need more support at home than is generally available. They also need access to appropriate specialist rehabilitation.

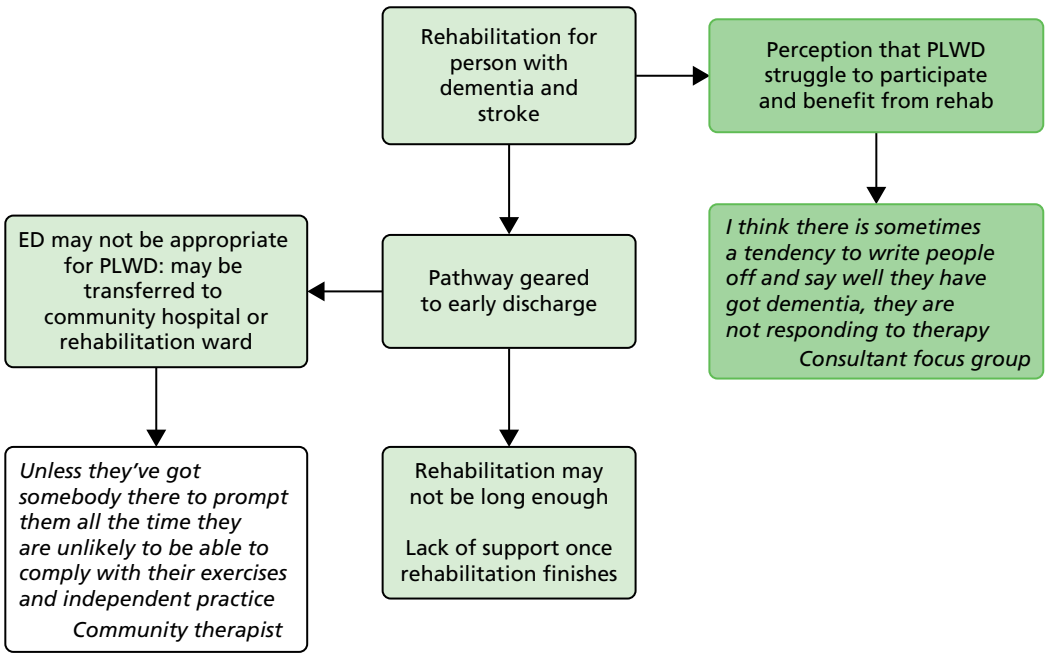

FIGURE 13 Potential problems with current stroke pathways for PLWD. ED, early discharge.

Systems not appropriate (not dementia friendly)

Health-care systems are often not dementia friendly. One frequently occurring example was around appointments, particularly in secondary care. PLWD and their family carers reported problems with remembering appointments (especially if they were booked over the telephone), difficulties with co-ordinating multiple appointments and problems with rescheduling and cancellations:

> *there was one clinic that he went to who wanted to make all the appointments by phone, so they would ring my parents . . . and say, 'Right, we'd like you to come in next Tuesday at ten o'clock', and dad would say, 'Yeah, right okay', and then he'd put the phone down and my mother would say, 'Who was that?' and he'd say, 'I don't know', 'What did they want?', 'Don't know'.*
>
> *Carer VI 3, south-east*

Missed appointments could result in PLWD being taken off the clinic list and having to be re-referred by their GP. HCPs reported that pressures to meet targets could lead to a zero tolerance approach to patients who failed to turn up for appointments.

Health-care professionals were aware that people with dementia often needed longer appointments but time pressures meant that this generally did not happen:

> *one of the things about eye clinics is you have to be aware that the normal process which is fairly intensive of getting people through the system and it takes an hour or so to get through, if someone's got dementia or learning disabilities you have to take that into account and how you handle them in the environment of the clinic, you know, they need more time.*
>
> *Ophthalmologist 1, London*

> *but actually it really requires time of talking to the patient I think to uncover those sort of issues to do with memory problems and we're not always very good at that I think.*
>
> *Ophthalmologist 2, East of England*

There was a lack of flexibility in health and social care that made it difficult for people with dementia and comorbidities. For example, HCPs reported that in some instances insulin regimens had to be altered to fit with the schedules of district nurses who could only visit at certain times of the day:

> *but if you're reliant on district nurses for example who got their own, you know, they've got their timetable of what they need to do in their work to get through, and they have to administer it at a set time and that can be incredibly disruptive to the individual.*
>
> *Diabetes consultant, diabetes focus group, south-east*

The split between social care and health care was also identified as a particular problem. Supporting PLWD to live independently at home is invariably seen as social care. This broke down when social services carers were not able to test blood sugar or oversee medication for people with diabetes, making it difficult to co-ordinate meals and medication and putting PLWD at risk of hypoglycaemia:

> *Yeah. Silly things like a simple blood glucose test or being taught how to recognise signs and symptoms of a hypo could prevent a whole admission or, yeah.*
>
> *Diabetes consultant, diabetes focus group, south-east*

A more cohesive provision of social and health services to patients in the community was seen to be particularly important by HCPs for PLWD and diabetes:

> *then just to simply tie up the medication and monitoring of diabetes with the provision of meals is basically all that needs to be done. And I think that's where it falls apart a lot of the time because people who can't self-manage will often be reliant on a district nurse or a community nurse to perhaps come in and oversee the medication or give them their insulin, but they won't be responsible for ensuring that that person has their breakfast or, so you get big gaps between one and the other and that really is not helpful. And that's how people do end up having falls and being admitted to hospital, yeah.*
>
> *Diabetes consultant, diabetes focus group, south-east*

Some of the problems with systems that are detailed above can be seen in the vignette in *Box 7*, which describes a specific case from an interview with a PLWD and his daughter. It also highlights how some HCPs do not have the skills and knowledge to deal sensitively with PLWD.

BOX 7 Systems are not dementia friendly

Mr C is an 89-year-old retired airline pilot with AMD and Alzheimer's disease. Mr C was already living with AMD when his daughter noticed that he was starting to forget things. She reports that it took her three or four telephones calls to the GP before she got her father referred for assessment. Her father was then diagnosed with Alzheimer's disease but they felt that the diagnosis was delivered in a blunt and insensitive way. Mr C was upset at this appointment and refused to attend the follow-up appointment. He currently receives no care from the Community Mental Health Team.

His daughter, who lives a long distance away, said that they struggled without any support for over a year. They then had help from social services but were unsatisfied with the support provided: multiple carers who came at various times and sometimes did not turn up at all. They now no longer use social services but pay for a private carer who comes in on a daily basis.

Mr C continues to get support for his AMD and reports a positive relationship with the consultant treating him for his vision problems. He feels that the consultant has taken the time to get to know him as a person and, as a consequence, he likes going there. However, the daughter recounts problems with hospital appointments being booked over the telephone. Mr C would forget to write down appointments and as the system allowed for only one telephone number to be recorded she was not aware when appointments had been made. She also said that hospital transport staff did not understand the needs of her father.

They reported a visit to an optician that had clearly distressed both Mr C and his daughter. When booking the appointment Mr C's daughter had explained that her father had Alzheimer's disease and may need more time. He was given a double appointment but during the eye assessment Mr C found it difficult to understand what he was supposed to do and this was upsetting for him. Mr C's daughter said that the optician did not understand her father's dementia and he kept communicating with her instead of her father. The optician then suggested that her father should go into a care home because of the risks of living at home with dementia and VI. The daughter was unhappy that he had made this comment in the presence of her father.

Environments not appropriate (not dementia friendly)

People living with dementia and their family carers reported a number of negative inpatient experiences including multiple bed moves, long waiting times for procedures, staff not being aware of the patient's dementia and staff not understanding the needs of PLWD. This often led to negative outcomes for the PLWD such as wandering and increased agitation, confusion and distress. There were also examples of a lack of understanding of the specific needs of people with dementia and particular comorbidities such as diabetes:

> *She had to leave here five in the morning, nil by mouth, she was told to get to H for eight and she didn't go down for her surgery until after three.*
>
> *She was distressed because she . . .*
>
> *By the time . . .*
>
> *. . . was so hungry and she, you know, with people with diabetes and they're hungry they get pain don't they in their head and things.*
>
> *Carers diabetes 7, south-east*

Health-care professionals also had concerns that hospital environments may not be safe or suitable for PLWD and that hospitalisation could lead to a deterioration in their condition. There appeared to be an expectation among some HCPs that PLWD will exhibit challenging behaviour while in hospital and that this will impact on the care of other patients. Some HCPs provided examples of dementia specialist wards or units where the focus was on person-centred care and where the environment was geared towards PLWD:

> *Actually on [name] ward it's fine, there's space and no one complains about them walking around the ward, it's actually quite fine simply walking around the ward. So I think that's hugely important that actually people aren't being penalised for trying to be mobile or hey, people are actively encouraged almost.*
>
> *Psychiatrist 1, south-east*

However, environments that specialised in care for our three comorbid conditions tended to be less dementia friendly. For example, in eye clinics patients often have to complete multiple tests over long periods and may need to attend appointments on a number of different days. There is also an emphasis on moving many patients through the clinic as quickly as possible. VI HCPs felt that PLWD would benefit from longer appointments but the current structure of their service made this difficult to implement.

Some of the potential barriers and facilitators for people with dementia and VI can be seen in *Figure 14*. The barriers are common themes that arose in the literature and have been summarised to illustrate a typical patient journey. The facilitators are things that were suggested as good practice by HCPs but which were often aspirational rather than current practice.

Comprehensiveness and equity of health care

Balancing risks and benefits

Access to care was affected by the ways in which HCPs and family carers weighed up the risks and benefits of treatments for PLWD, such as surgery for cataracts or thrombolysis for stroke. Some of the factors involved in making decisions about care for people with dementia who have had a stroke are illustrated in *Figure 15*.

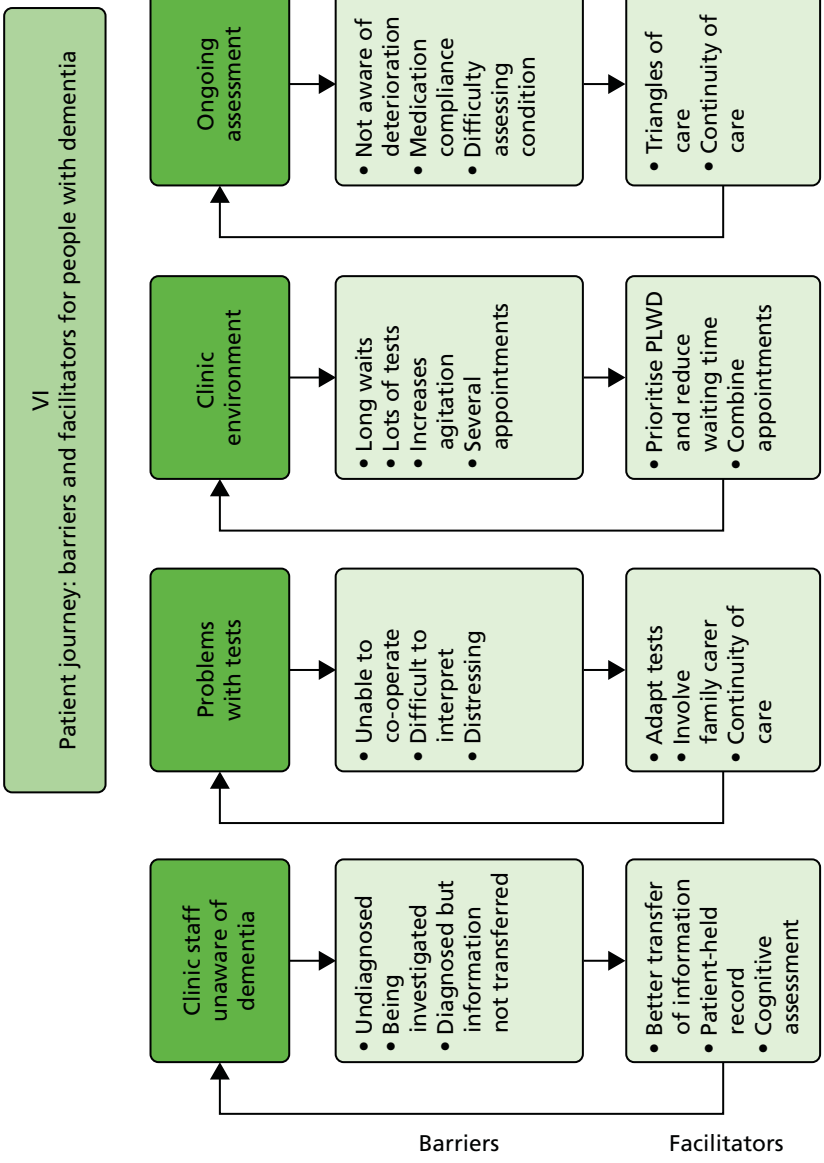

FIGURE 14 Barriers to and facilitators of care for people with dementia and VI.

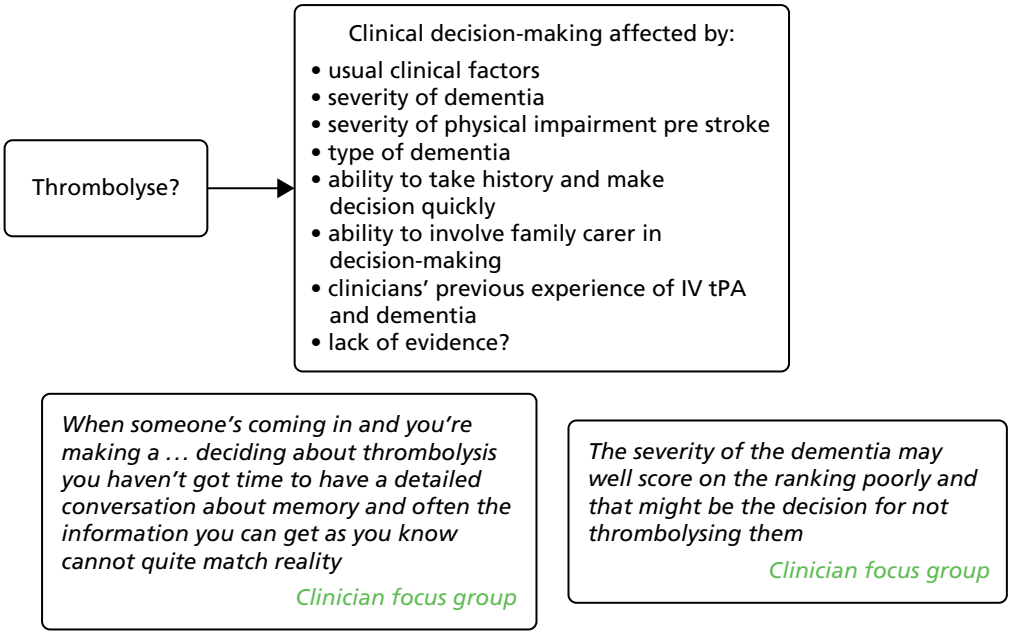

FIGURE 15 Factors involved in decision-making for people with dementia who have had a stroke.

Factors that impacted on clinical decision-making across the three comorbidities included concerns about polypharmacy, a PLWD's ability to co-operate with treatment, the ability to gain meaningful consent, severity of the dementia, levels of multimorbidity, the availability of support from a family carer and the presence of a family carer to act as a proxy and provide information.

It was clear that attitudes towards risk differed among clinicians. For example, in one focus group there were different opinions about the safety of taking someone off insulin:

> *it's also going to be very risky to take them off insulin.*
>
> *Diabetes consultant, diabetes focus group, south-east*

> *you may decide that a blood sugar range of 5–15 is quite adequate for that person and you may be able to achieve that without insulin, so it is a question I do ask myself when I look after people's diabetes, you know, is that something that we could safely offer.*
>
> *Diabetes consultant, diabetes focus group, south-east*

There were some data to suggest that attitudes towards risk were affected by previous experiences:

> *I wouldn't refer someone who was uncooperative . . . I have had a patient who got up in the middle of a cataract operation and refused to have anything further done and lost the vision in his eye.*
>
> *GP 4, south-east*

It is also possible that attitudes towards risk change over time and as a HCP gains experience:

> *I think as you get more experienced, it's quite a difficult decision but as you get more experienced your decision changes. I'm certainly quite . . . personally, I don't know how others are but I certainly am quite aggressive about cataract surgery in people with dementia, I think that it's got a very low downside, the chances of something going wrong are very remote and if you make it work and you make them function better then fine.*
>
> *Ophthalmologist 1, London*

Health-care professionals' expectations and attitudes

Clinical decisions were influenced by HCPs' attitudes and previous experiences of treating PLWD. There were contrasting attitudes towards the benefits of performing cataract surgery for PLWD. For example, one consultant was concerned about a lack of co-operation during surgery and thought that the benefits of improving vision for PLWD were sometimes 'overplayed a bit' (ophthalmic surgeon, VI focus group, East of England), whereas another was more positive about the benefits of surgery for PLWD:

> *I'll do cataract surgery on most people because I believe it's a very powerful intervention to make and the downsides are very low, different people have different attitudes, say in terms of the surgeon.*
>
> *Ophthalmologist 1, London*

There appeared to be an expectation among stroke clinicians and therapists that PLWD would not be able to co-operate with or benefit from rehabilitation, particularly if they had challenging behaviour.

Candidacy

Candidacy refers to the concept that access to health care is jointly negotiated between individuals and health services. For PLWD, family carers were key to this process, often acting as an advocate for their family member with dementia:

> *As a family member you're the person who knows that person better than anyone else so you can see when it's not, when it's not right, when it's going wrong.*
>
> *Carer diabetes 4, south-east*

> *It was like when she had her cataract done, I actually went into the room with her . . . you know, because one nurse at the cataract kind of looked at me and she said 'no, if you wait in the waiting room', I went 'well, no – my sister has a memory problem so I'll have to stay'.*
>
> *Carer diabetes/VI 6, south-east*

They were often also responsible for noticing when something was wrong and seeking help from the appropriate services. For example, one daughter noticed that her mother's feet were going black:

> *Her feet were black and I was concerned, because we've got, in the paternal side of my family, she's got aunts and her mother was blind, aunt had amputation of the toes.*
>
> *Carer diabetes/VI 3, south-east*

However, it had often taken carers some time to understand how systems worked, who to contact and what questions to ask. HCPs also recognised that those PLWD who lived alone or who did not have support from a carer were particularly vulnerable and may have poorer access to care:

> *the greatest difficulty is when that individual lives alone and doesn't have an able partner, because then their care can become very disjointed or they're not, they're not able, often they, an appointment's made or they, and they won't answer the door or they forget and so it's when somebody's on their own that you have the biggest issues and lack of joined-up care.*
>
> *Physiotherapist 1, south-east*

Health-care professionals' understanding/appropriate training

Many of the HCPs in our study, and across the three target conditions, appeared to feel unprepared to care for PLWD. Some of the HCPs referenced learning or training that was specific to the treatment and care of PLWD but this had been brief and did not appear to have impacted on practice:

> *I think a lot of people are aware that there hasn't been apart from that one-off training that I've had recently, I haven't seen a huge change in practice for dementia patients.*
>
> *Physiotherapist, stroke focus group, south-east*

Diabetes nurses in one focus group admitted that they had very little knowledge about dementia, and stroke physiotherapists in another group said that they had not received any dementia training. HCPs in the VI focus group said that they would like some dementia training to raise awareness in their field:

> *Just training really, just I think we just need that extra training just to, in this particular aspect, clinical and awareness of what to do.*
>
> *Senior orthoptist, VI focus group, East of England*

People living with dementia and their family carers provided many examples in which they felt that HCPs had not understood their needs, for example transport staff with no knowledge of dementia, clinic staff asking PLWD for details such as their medical history or date of birth that they had difficulty remembering or HCPs giving patients complicated medication regimes that they were unable to manage.

Screening and monitoring for long-term conditions

Access to appropriate screening and monitoring for people with conditions such as diabetes appeared to vary considerably, for example ranging from weekly home visits for some patients to irregular telephone monitoring for others. Some people reported that they were satisfied with the monitoring that they received for their condition whereas some carers of PLWD with diabetes were concerned that their relative was not receiving adequate monitoring. Diabetes specialist nurses and GPs expressed concerns that patients were not getting appropriate screening for their condition, such as foot checks. This was particularly a concern for housebound patients and those who lived alone:

> *And I think it's only when [name of diabetes nurse in focus group] goes in that she can actually see, you know, that the devastation or whatever that's been caused by possibly years and lack of input.*
>
> *Diabetes specialist nurse, diabetes focus group, London*

People living with dementia and their carers were often unclear about whether or not they were getting adequate foot checks and there was confusion over the different roles of chiropodists and podiatrists.

There were also problems with tests that were not geared towards PLWD:

> *she said you know, 'can you read the third row of the chart' or whatever he couldn't, and she twigged that there might be a problem and called me in, I said 'well he's got dementia', it's on his diabetic notes but it obviously hadn't gone through to the eye screening bit, so I think she tried him with numbers, he's probably a bit better with numbers than he is with letters.*
>
> *Carer diabetes 1, south-east*

Health-care professionals also reported difficulties carrying out eye tests with PLWD and in some cases tests could not be carried out:

> *I get some dementia patients come the AMD clinic and usually with a carer of some description, and then we have the difficulty of assessing their vision because of them not being able to verbalise what they're seeing, difficulty reporting symptoms.*
>
> *Staff nurse ophthalmology, VI focus group, East of England*

Patients with diabetes, stroke and dementia should receive routine monitoring as part of the QOF. However, it was clear that there was variation in the way that these assessments were delivered and GPs expressed concerns about whether or not all patients received these assessments, particularly those who were housebound. The dementia QOF appeared to be considered less of a priority than those for diabetes and stroke:

> *I think the diabetes, the heart disease, the stroke, you know, all those you know are more mainstream as it were, the ones that were given a lot of time and I think yes the dementia one would probably have been left, I certainly think we do achieve the QOF targets for it, but it is perhaps not at the forefront of people's mind in the way that the diabetes one is, you know I suppose in terms that we don't have a protocol for it, you know that wasn't something I even and it hasn't even kind of crossed my mind to be honest.*
>
> *GP 8, north-east*

Conclusions

Continuity and appropriate access to care were key for people with dementia and comorbid conditions such as stroke, diabetes and VI. Clearly, continuity and access are linked, with continuity of care being a facilitator of appropriate and comprehensive health care for people with dementia. However, although continuity is important to people with dementia and their family carers, it is often lacking. The transfer of information between specialties, such as a diagnosis of dementia, seems to be a particular problem. Family carers in our study played a significant role in facilitating both continuity of care and access to care.

Many of the issues highlighted in this chapter are applicable more generally to people with long-term conditions or complex health needs, not just those living with dementia. However, many of these problems are compounded by dementia. For example, although many carers may be playing a role in co-ordinating and managing care for a relative, this is perhaps more acute for PLWD who lack candidacy and are often completely reliant on family carers for facilitating continuity and access. Care for PLWD needs to be reframed as a three-way process between the HCP, the PLWD and the family carer.

There are a number of barriers to continuity and access to care for PLWD. Some of these are condition specific but many are applicable across the three conditions. For example, although there are specific concerns about preventing hypoglycaemia for people with dementia and diabetes, many of the issues are applicable to all three comorbidities, such as managing medication, providing co-ordinated services and supporting carers. The data provide some examples of effective care for PLWD but many of these examples seemed to be about the individual health providers that patients and carers encountered rather than about systems-based approaches.

Chapter 7 Consensus conference

The consensus conference

Findings from phases 1 and 2 of the study were discussed with key stakeholders at a consensus conference at the Royal College of General Practitioners in December 2014. This was a half-day event and was attended by 40 participants, including practitioners specialising in the care of people with our target comorbidities (diabetes, stroke and VI), GPs, service managers and commissioners, members of the public and representatives from the third sector involved in supporting people with dementia (e.g. Alzheimer's Society, Carers in Herts) or people with our target comorbid conditions (e.g. Stroke Association, Diabetes UK, Thomas Pocklington Trust). The event was facilitated by Professor Steve Iliffe.

The more specific aims of the consensus meeting were to:

- consider how current services can adapt to meet the needs of PLWD who have other complex health-care needs
- develop guidance about how services might be developed to engage better with PLWD and their unpaid carers, indicators of quality that can inform commissioning of services for older people and specialty-specific guidance on assessment and decision-making.

To structure the discussion and rank the importance of the findings and their relevance for service improvement and delivery we used a nominal group technique.[86,87] Participants were split into four small groups around their area of specialty (i.e. stroke, diabetes, VI and general practice). Based on the evidence presented by the research team and their own experiences, participants were asked to consider what changes they would recommend to improve care for people with dementia and comorbidity. Group facilitators asked each person to silently and independently generate ideas/recommendations. Ideas/recommendations could be general or specific to one of the three target comorbidities. After the generation of ideas, group facilitators invited participants to share their ideas with the rest of the table and once all ideas had been presented the facilitators encouraged discussion around how these concepts could be developed and implemented. To filter and prioritise the ideas/recommendations, the facilitators asked the groups to choose the top two ideas and these were refined through further group discussion. Finally, the event facilitator consolidated the ideas/recommendations by asking each table to put forward their 'best ideas' to the larger group.

After the meeting, ideas from each group were documented and summarised.

Cross-cutting themes

There were a number of cross-cutting messages that arose from the discussion (*Box 8*).

BOX 8 Cross-cutting messages from the consensus meeting

- The presence of dementia complicates the delivery of health care in what is often already a complex situation involving patients with multimorbidity and/or frailty.
- Many HCPs reported that they and their colleagues feel underprepared to care for PLWD and better education and training for staff is required.
- Better integration and co-ordination of care are needed, between primary and secondary care and between different specialities in secondary care.
- There is a need for better record sharing and transfer of information; current systems such as 'This is me' could be expanded to include health-care information.
- PLWD and their family carers need support (from either a professional or a trained lay person) to help navigate health-care systems in primary and secondary care.
- The QOF dementia review needs standardisation and could include physical health checks (e.g. vision), assessment and care planning.
- Disease-specific pathways (e.g. diabetes, stroke, VI) need to be adapted to meet the needs of PLWD.
- There may be transferable learning from other areas, in particular the area of learning disability.
- When appropriate unpaid carers need to be included in care planning and decision-making and provided with adequate support.

Ideas/recommendations and supporting evidence

The outputs of the discussion were grouped into five overarching categories: (1) integration (including information transfer), (2) co-ordination and navigation, (3) optimising current systems and care pathways, (4) workforce development and (5) including and supporting family carers. In the following sections we outline the main implications for practice in each of the categories and discuss them in light of existing evidence (see *Chapter 3*).

Integration

Evidence from the consensus meeting and the interviews and focus groups highlighted the problems caused by barriers between primary and secondary care and between different specialities in secondary care (e.g. between mental health services for dementia and physical health/older people's services). Participants at the consensus meeting suggested a number of strategies for improving the integration of care.

Integrated practice

One suggestion for integrating primary and secondary care was the extension of the concept of integrated practice units (IPUs), with co-located care and access to shared health and social care budgets.[165] Porter and Lee[165] suggest that the IPU should provide the full care cycle and treat not only the main condition but also related conditions and complications (such as eye disorders in people with diabetes). Within the UK there is a strong policy push towards better integration of care,[166–169] which is seen as particularly important for addressing the needs of older people with complex health needs.[170] The *Five-Year Forward View*[166] sets out the new care models programme, which includes integrated primary and acute care systems and multispecialty community providers. The aim of primary and acute care systems is to join up GP, hospital, community and mental health services and the aim of multispecialty community providers is to shift specialist care out of hospitals into the community. A number of vanguard sites will trial these models of care.[171]

Although there are currently few formal evaluations of IPUs, as described by Porter and Lee,[165] there are a number of systematic reviews that have looked at the effectiveness of initiatives for integrating care systems for older people.[172–174] One review of integrated funds for health and social care found mixed evidence of impacts on health outcomes, costs or resource use.[173] Barriers to integrated budgets included difficulties in implementing financial integration and differences in performance frameworks, priorities, governance and information systems. However, none of these reviews focused specifically on integrated care for people with dementia and comorbid health conditions and there is limited evidence on the care of patients with multimorbidity.[174]

Integration on a smaller level was also recommended, for example linking community opticians and optometrists with memory clinics. A recent retrospective audit found evidence to suggest that a combined clinic with neurological, ophthalmic and psychiatric input is a potentially effective way to diagnose and manage complex vision problems in older people, including those with cognitive impairment.[175]

Multidisciplinary assessment

Several groups recommended the use of multidisciplinary assessment and care. For example, diabetes specialists suggested a programme of joint assessment and review (with old-age psychiatrists) for people with diabetes who are diagnosed with dementia. There is evidence to support the use of comprehensive geriatric assessment (CGA) for older people.[176,177] A Cochrane review of CGA concluded that older people were more likely to be alive and in their own home after CGA.[178] The authors suggested that wards designed for CGA seem to be more effective than mobile teams. A UK study of CGA for older people considered to be at high risk of future health problems failed to show an effect on patient outcomes or subsequent use of secondary care, but the authors concluded that this was because their intervention did not deliver truly comprehensive CGA.[179]

Information transfer and personalised information

Our qualitative data suggest that the transfer of patient information between professionals in different specialities and settings is a problem for patients, family carers and HCPs. This was reiterated by participants at the consensus conference. VI specialists recommended a system for flagging up a dementia diagnosis on records to ensure that specialists such as optometrists know when a person has received a dementia diagnosis. It was also suggested that the next of kin details for people given a dementia diagnosis should be clearly marked on GP records and that, with the consent of patients, family carers should be routinely copied into letters. This would help keep family carers informed and help to facilitate access to services for people with dementia.

Ideas/recommendations for improving information transfer also included the use of patient-held records, either electronic or paper, that could facilitate the sharing of information among patients and their carers, primary and secondary health care and social care. User-held records are part of an innovative memory service provided within a GP practice in Staffordshire.[180] Older people or their carers are supplied with hand-held applications to help co-ordinate their care, control their own records and trigger appropriate urgent support when required. The scheme has been well received by older people and their carers and there is some evidence to suggest that delivering this model has released savings in acute hospital activity.[181]

It was also suggested that information transfer for people with dementia could be facilitated by expanding the ‘This is me’ document to include more health-related information. Participants cited schemes for people with a learning disability, such as the purple folders used in the West Hertfordshire Hospitals NHS Trust.[182] The ‘This is me’ document was designed for people with dementia who are receiving professional care in any setting. Although its use is supported by the Alzheimer’s Society and the Royal College of Nursing, it has not been formally evaluated.

Co-ordination and navigation

Case management and care co-ordination

Case management for people with dementia and comorbidity was suggested by several groups as a way of assisting people with dementia to navigate health systems and improve their access to care. A number of systematic reviews have been reported of studies assessing the impact of case management on older people with dementia.[183–189] In general, studies have provided conflicting information about the potential benefits and duration of effect of case management for people with dementia. A recent Cochrane review of case management for PLWD found that the case management group was significantly less likely to be institutionalised at 6 and 12 months than those not receiving case management, although the longer-term effects were uncertain.[187] The authors found no significant differences in hospital admissions, mortality or patients' or carers' quality of life.

Assessing the impact of case management is complicated by the variety of models and differences in the way that the role is interpreted.[188,190] Differences include the type of care provided, the degree of collaboration and integration with other HCPs and the professional background of case managers.[191] Furthermore, it is not clear which population of people with dementia is most likely to benefit from case management and at what stage of the dementia trajectory.[185] Studies have, however, identified a number of characteristics that appear to be important for the success of case management and care co-ordination. These include strong provider and care networks, good personal connections with other HCPs, expert knowledge, embedding in the multidisciplinary team, the involvement of GPs, intensive and proactive approaches and clearly defined skills and responsibilities.[184,188,192–194]

An example in which care for people with dementia is reported to have been successfully co-ordinated in the UK is the Oxleas Advanced Dementia Service, which provides care co-ordination, palliative care and support to people with advanced dementia living at home.[195] The authors of this report provide key lessons that they have learned: the need to provide care and advice to family carers; strong links between physical and mental health services; acceptance of referrals from a wide range of HCPs; a single comprehensive assessment of the patient and carer that addresses physical, mental health and social care needs; for a personalised care plan; and dedicated care co-ordination by a specialist nurse with suitable case management skills.

Dementia co-ordinators/support workers

Another recurring idea/recommendation involved the use of dementia co-ordinators or support workers to help people with dementia navigate health services. For example, one group suggested the use of dementia nurses in each hospital who would liaise between staff, relatives and the community and follow patients through their hospital stay. However, although it has been suggested that dementia specialist nurses with clearly defined roles could benefit people with dementia, there is little direct evidence for the effectiveness of dementia specialist nurses in hospital settings.[48,196] Moreover, there is anecdotal evidence to suggest that some specialist teams, such as those for palliative care, can have negative impacts, such as disempowering or deskilling other HCPs.

Parallels were drawn with learning disability liaison nursing, in which specialist nurses provide support for people with learning disability admitted to hospital. However, although there is evidence to suggest that learning disability liaison nursing is valued by stakeholders,[197] and that promoting access and equity is an important part of the role,[198] there appears to have been little formal evaluation of the role[199] and its impact is unclear. Others suggested that the role of a dementia navigator could be non-clinical. For example, it was suggested that the role of the Stroke Association Life After Stroke Coordinators could be extended to include support for people with dementia who have had a stroke. There is some evidence to suggest that non-clinical dementia advisors can have a positive impact on PLWD and their family carers[200,201] but there is a need for further testing of such schemes.

Optimising current systems and care pathways

There were ideas/recommendations for all groups that focused on ways of improving and optimising current systems. One such example was around the QOF in primary care. Currently, the structure or content of a dementia review is not clearly specified and there is variability in practice. It was suggested that the dementia QOF could be standardised to include physical and mental health checks, including checks for vision and hearing. Again, parallels were drawn with services for people with a learning disability, in which health checks have led to the detection of unmet need and allow for targeted actions to address health needs.[202]

There was recognition from participants that current pathways may not be appropriate or suitable for PLWD. Diabetes specialists suggested that there is a need to reframe what 'good' diabetes care is for PLWD and a need for better guidance about what is important and essential in diabetes management, for example whether or not it is possible to simplify diabetes management for PLWD. A recent best clinical practice statement by a multidisciplinary National Expert Working Group provides a pathway that integrates diabetes and dementia care[147] and which is less reliant on self-management than standard diabetes pathways.[203] However, there is little in the way of formal evaluations of strategies for managing diabetes in people with dementia.[59]

Suggestions for stroke care included improving the accident and emergency pathway for transient ischaemic attack patients with pre-existing dementia to ensure that scans were carried out on the same day rather than assessing patients and then sending them home with a referral form. Participants also proposed that current assessments such as the 6-month post-stroke review and the annual review in primary care could be improved, for example being used to pick up changes in cognition. VI specialists suggested that the eye care pathway for PLWD should include information about eye examinations (including the availability of domiciliary eye tests), longer appointments, fast tracking for treatment such as cataract operations and subsidies for spectacles. However, implementing longer appointments would require additional funding as opticians are currently paid based on appointment times of 20 minutes.

Workforce development

Participants in both primary and secondary care suggested that there was a need for improved education and training for staff to raise awareness around dementia and improve services for PLWD. In some instances, training needed to be specific rather than generic, for example training staff working in stroke care how to modify rehabilitation for PLWD. VI specialists recognised a need to raise awareness of dementia among staff with training that included information on recognising and managing dementia, tailoring assessments to PLWD, signposting to appropriate services and guidance on how to optimise the environment for PLWD. Although there has been considerable investment in dementia awareness and training this has tended to focus on support workers and nurses[204] and has been generic rather than geared to the specific needs of people with dementia and comorbidities such as diabetes or stroke.

Including and supporting family carers

Participants at the consensus conference recognised the central role that family carers often play in the care of PLWD. Stroke specialists suggested that family support could be used to improve access by PLWD to services such as rehabilitation, for example by developing partnership rehabilitation involving PLWD, family carers and professionals. It was also recognised that family carers of people with dementia and diabetes often take on responsibility for giving medication, managing diet, etc., and that they may need additional education and support to equip them for this role. Although there has been research around support for family carers, this has tended to involve more generic interventions such as case management and educational and psychosocial support.[48] There is little research that looks at the specific needs of carers of people with dementia and medical comorbidities such as diabetes or VI.

Conclusions

It is clear that the presence of dementia complicates the delivery of health care in what is often already a complex situation involving patients with multimorbidity and/or frailty. Many of the ideas that arose were not just applicable to people with dementia and it is challenging to disentangle what are essential components of dementia care and what are components that are applicable to all older people with complex health and social care needs. The situation is further complicated as some people will develop comorbidity in the presence of already diagnosed dementia and others will develop dementia subsequent to a comorbidity such as diabetes, stroke or VI. The profiles and needs of these groups may be different. Furthermore, dementia is a syndrome and not one condition and, within that, there will be a range of people, from those who are able to self-care to those who are very frail and need palliative care.

Although some of the ideas/recommendations were specific to our three tracer conditions, many of the ideas/recommendations drew on similar concepts, in particular the need for better integration and co-ordination of care, improved transfer of patient information, support for PLWD and their unpaid carers to navigate health systems, training and education for HCPs, recognition and support for unpaid carers and the improvement of current systems to better meet the needs of PLWD who have other health-care needs.

In the next chapter we bring together the findings from each phase of the study to map current models of care, look at how the presence of dementia with one or more comorbid conditions is currently being addressed by service providers, highlight interventions that might support continuity and equity of access to care and outline the implications for clinical practice and research.

Chapter 8 Discussion

The overall aims of this study were to explore the impact of comorbidities for a PLWD on access to non-dementia services and identify ways of improving the integration of services and reducing fragmentation of care. We focused specifically on three conditions: diabetes, stroke and VI.

We used a mixed-methods approach including:

(a) a scoping review of relevant literature to map what is currently known about comorbidity and dementia
(b) a cross-sectional analysis of a population cohort database to explore health and social service use in people with a diagnosis of dementia and a comorbid medical condition
(c) a qualitative study exploring the views and experiences of people with dementia, their family carers and HCPs
(d) consensus methods to help develop ideas/recommendations for practice.

In this chapter we start by giving an overview of the findings and then go on to discuss the limitations of the study and the potential implications of the findings. We finish by outlining the implications of our findings for practice and future research.

Summary of the findings

Scoping review

We included 76 studies or reports that addressed issues around dementia and comorbidities (diabetes, stroke and VI). There was evidence of a lack of continuity in health-care systems and structures for people with dementia and comorbidity, with little integration or communication between different teams and specialities.[72] Moreover, many models of care are focused on single diseases and do not take into account the needs of those with multimorbidity.[4,91] Twenty-six studies reported prevalence data,[1,2,12,14,20,69,91,101,103,104,118,119,121,127–129,134,137,140–146], either of one of our three target comorbidities in people with dementia or of dementia in people with stroke, diabetes or VI. Although heterogeneity in the populations and differences in the way that conditions were ascertained make comparisons across studies difficult, the data do suggest that the rate of diabetes in people with dementia may be between 13% and 20% and the rate of stroke may be between 16% and 29%. Of the 11 studies[98,110,117,118,123,129,136,139,145,155,161] that compared access to treatment or receipt of services in groups with and without dementia, 10[98,110,117,118,129,136,139,145,155,161] found some evidence that people with dementia were less likely to receive the same quality of care or access to services than those without dementia.

Analysis of the Cognitive Function and Ageing Study data

In CFAS II the prevalence of dementia in those living in the community was 5.3%. Of these people with dementia 17% had diabetes, 18% had had a stroke and 17% had VI. The aim of the CFAS II-only analysis was to see whether or not there was any difference in service use between those with dementia and a target health condition and those with dementia alone or the health condition alone. Of all of the services, unpaid care was the most commonly used service in CFAS II. When comparing unpaid care use between those with dementia and a target health condition and those with only the health condition, in every case unpaid care was used considerably more by those with dementia and a target health condition (see *Appendix 5*). As well as unpaid care, those with dementia and a target health condition also used a home care assistant, a care worker and a day centre more than those with the health condition alone. When comparing hospital service use between those with dementia and a target health condition and those with dementia alone, inpatient services were used more by those with dementia and a target health condition.

The comparison analysis between CFAS I and CFAS II looked at whether or not there were any differences in service use over the last decade. The main difference seen was in the use of day-to-day services, which

decreased substantially over this time period because of a decrease in the use of meals on wheels, paid help and care workers. At the same time there was a marked increase in the use of unpaid care by those with dementia and either diabetes or VI. Unfortunately, the numbers were not large enough to test this formally.

Interviews and focus groups

We conducted interviews with 28 people with dementia and 33 family carers, and focus groups or interviews with 56 HCPs. The analysis was informed by the different dimensions of continuity[46] and access to care.[34] Our two overarching themes were (1) negotiating continuity with respect to relationship, management and informational issues and (2) negotiating access to care, including appropriateness, comprehensiveness and equity for PLWD and comorbidity. For a summary of the themes and subthemes see *Figure 11*.

Negotiating continuity

People living with dementia and their family carers valued relationship continuity. In particular, the personal characteristics of HCPs, and the communication of information in a timely and sensitive manner, appeared to be key to developing a trusting relationship with a HCP. Relationship continuity did not always have to be with an individual but could be with a team, although this was dependent on good record-keeping and transfer of information between members of the team. Interviews with HCPs highlighted the way that relationship continuity facilitates access to health care for vulnerable patients.

Although some PLWD were still able to manage their condition and navigate health services, this was either because they were in the early stages of dementia or because of support provided by family carers. Family carers were often playing a significant role in managing and co-ordinating the care of their relative; this sometimes involved having to learn new skills such as checking blood sugar or giving insulin injections. The transition from self-management to dependency could be gradual or sudden (e.g. after a hospitalisation) and was often unpredictable or understood only in hindsight. HCPs whom we spoke to acknowledged the vital role that family carers played but from carers' accounts it was clear that this recognition did not translate into their routine involvement in patient appointments or decision-making about the care of their family member. As in other studies we found that staff concerns about confidentiality may impede carers receiving information.[205]

The absence of a standardised approach to sharing information about a person's dementia and how it might affect the management of other conditions was a recurrent issue. This had implications for how appointments were planned and organised and how carers were involved. There appeared to be no cross-discipline approaches that supported the meaningful transfer of information about a person's dementia and related disabilities; HCPs involved in delivering care for people with our target comorbidities commented that they were often unaware that someone had dementia. Instead, informational continuity was often provided by family carers attending appointments and transferring information between specialities. Despite evidence of awareness among staff that PLWD could need more time for consultations, clinic structures and pressures of patient numbers meant that there was generally little capacity to do this for PLWD. We found little evidence of services developing processes to support informational continuity or using tools such as 'This is me' to support continuity of information.

Negotiating access

Our interviews and focus groups provided many examples in which systems or environments had unintentionally blocked access to care for PLWD, for example appointments made over the telephone, long waits in busy clinic environments, tests that were not appropriate for PLWD, new technology introduced without proper explanation, lack of involvement of family carers and a failure to engage with social care. Pathways and guidelines for our three target conditions did not address the possibility of a dementia diagnosis or provide decision-making support for practitioners trying to weigh up the risks and benefits of treatment for PLWD. Moreover, many HCPs in our study reported that they felt underprepared to care for PLWD. There were examples of good practice but this tended to be about the behaviour of individual practitioners rather than about system-based approaches.

The care and treatment that PLWD received were influenced by the expectations and attitudes of clinicians. Decisions about treatment were made in the context of concerns about polypharmacy, consent, concordance (including for medication, tests, rehabilitation and surgery), the severity of dementia, multimorbidity and frailty. Clinicians also had varying perceptions of the potential benefits of treatment for PLWD, with some expressing positive views about treating PLWD and others being more pessimistic and risk adverse. There was a suggestion from the interviews and focus groups that HCPs may sometimes have a negative attitude towards the ability of PLWD to participate in, or benefit from, certain treatments, such as post-stroke rehabilitation.

The consensus conference

The consensus conference was a half-day event attended by 40 participants including practitioners, service user representatives and academics. Discussions from the meeting were grouped into five overarching categories. These categories and some of the associated models of care are shown in *Figure 16*.

Although some of the models of care referred to by participants were specific to our three tracer conditions, many drew on similar concepts around integration, co-ordination, support for family carers and workforce development. However, evidence for many of the interventions identified, such as integrated or collaborative models of care, is currently limited, local and based on case study approaches.[206]

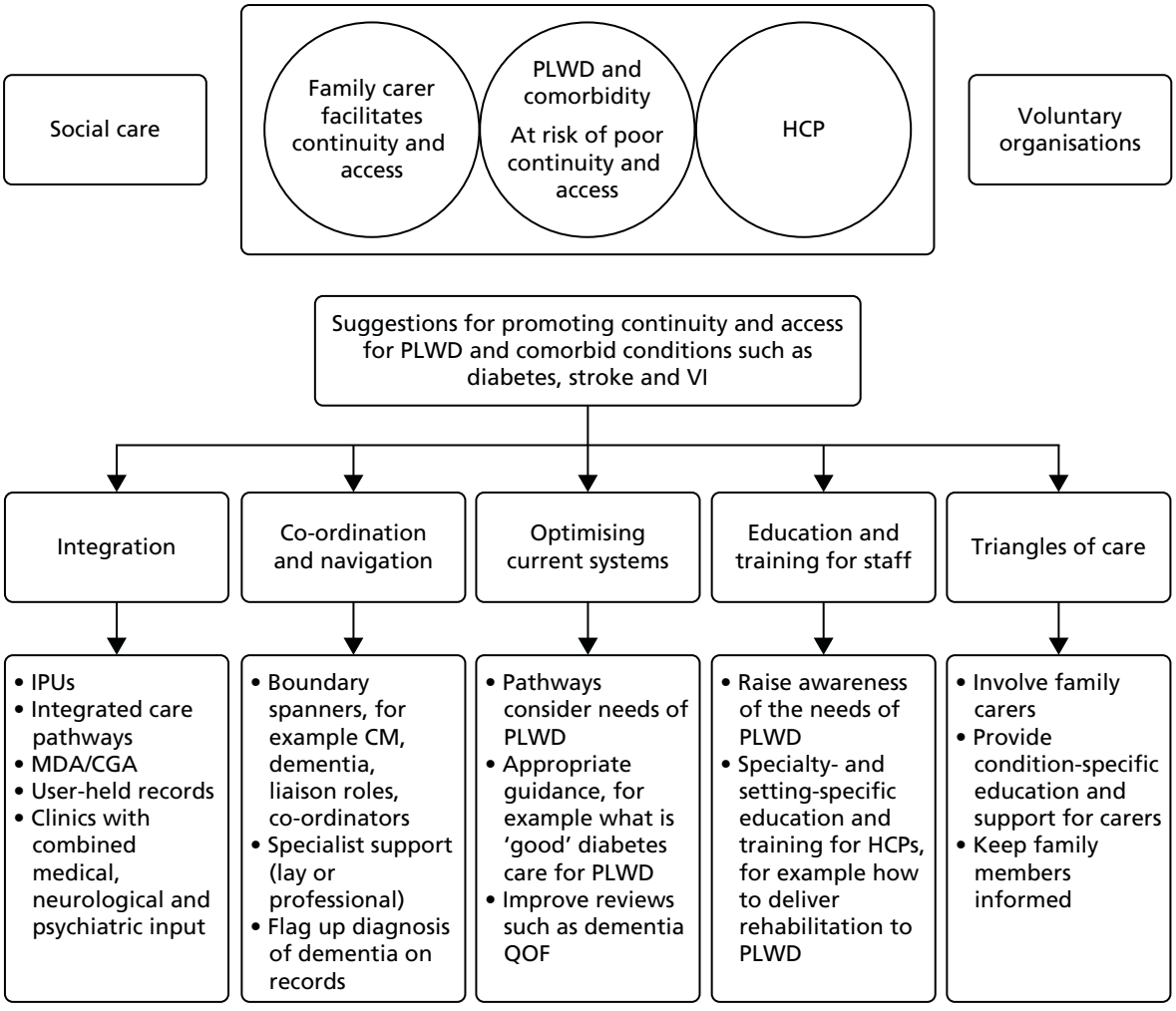

FIGURE 16 Summary of outputs from the consensus meeting. CM, case management; MDA, multidisciplinary assessment.

Limitations

We focused on three tracer conditions and it is possible that our findings may not be applicable to people with dementia who have other long-term conditions such as arthritis or chronic obstructive pulmonary disease. However, there were many cross-cutting themes and issues across our three conditions that are likely to be generalisable to other comorbidities. The focus of our study was on single comorbidities rather than multimorbidity and we excluded those living in care homes where there are likely to be considerable levels of dementia and comorbidity.[207] The support that people with dementia and multiple health conditions need may be different from the support required by those with less complex needs. Moreover, our study did not distinguish between those people who developed a comorbidity in the presence of already diagnosed dementia and those who had a health condition such as diabetes and who then developed dementia. The profiles and needs of these groups may be different.

The scoping review

We undertook a scoping review rather than a systematic review. A limitation of such an approach is that the review did not include an assessment of the quality of the included studies or evaluate the effectiveness of interventions. However, evaluative research in this area is limited and our aim was to examine the extent, range and nature of research activity around patient and carer need, health-care provision and service organisation for people with dementia and comorbidity. Although we did not undertake formal quality assessment we did extract methodological information on study populations and data collection methods that aided in the interpretation of the evidence. We set out to include a representative rather than an exhaustive range of literature and it is possible that we have missed relevant studies or guidelines. However, our search strategy was guided by systematic review methodology and we employed extensive database and lateral searches. We are confident, therefore, that the scoping review provides a comprehensive summary of current evidence relating to dementia and comorbidity for people living in the community, particularly in relation to diabetes, stroke and VI.

The Cognitive Function and Ageing Study analysis

Both CFAS I and CFAS II were large population-based studies that included random samples of primary care lists representing institutions and community-living people aged ≥ 65 years. The advantage of this is that they provide an accurate representation of the population at both time points. Over the last two decades clinical consensus on the diagnosis of dementia has been prone to change but the use of the GMS-AGECAT algorithm to give a study diagnosis of dementia in both CFAS I and CFAS II means that the results from the two studies are directly comparable. Unfortunately, low numbers in the target health condition groups meant that formal testing of any changes between CFAS I and CFAS II was not possible. The main limitation of this phase of the study is that, in CFAS I, to conduct analysis on service use only the 10-year follow-up wave could be used as the questions on service use were only introduced at this stage. This automatically meant that only survivors at the 10-year follow-up were included in the analysis. As well as restricting the CFAS II comparison analysis to those aged ≥ 75 years, inverse probability weights for attrition were used for the CFAS I analysis. However, even with the use of weights there was still some uncertainty around the estimates that could not be accounted for because of the low numbers of people who had stroke, diabetes and VI.

The cross-sectional design of this study means that no direction of causality can be inferred. Although CFAS I does include longitudinal data, the rate of attrition at the 10-year follow-up, when the service use questions were introduced, resulted in numbers that were too low for longitudinal analysis to be carried out. Between CFAS I and CFAS II, non-response at baseline increased from 23% to 44%. Inverse probability weighting was introduced to account for this population representation at each time point. Because of the low numbers services were grouped together for a more general analysis, but a limitation of this is that hospital use data were collected for a different time period from data on the use of day patient or outpatient services. Item non-response meant that in certain cases the analysis for some of the services could not be carried out. If information was not available from the participant interviews the informant interviews were used to fill in gaps when possible. Although informants may not always give the same responses that participants with dementia would have given,[208] this did still provide valuable extra information.

Interviews and focus groups

Our original intention was to recruit equal numbers of participants with stroke, diabetes and VI. However, we found it easier to identify and recruit people with dementia who had diabetes and more difficult to recruit people with dementia who had had a stroke. Furthermore, we recruited most participants through memory clinics or primary care and in most cases the stroke was not a recent event. Participants' recall of the care and treatment that they had received may not have been completely accurate and/or may not reflect current practice in stroke care.

Although qualitative research does not generally set out to be representative, it is appropriate to consider the transferability of findings. HCPs in our study were a self-selecting sample who were willing to have their practice examined. As such, it is possible that they may have had more awareness of the needs of PLWD and more interest in their care needs than their colleagues. However, the accounts of HCPs were validated against the accounts of PLWD and their family carers.

Like much qualitative research with people with dementia,[23] the majority (78%) of our participants with dementia lived with a family carer and we are able to say less about the experiences of those who live alone. Moreover, although we included two geographical areas, most participants lived in urban areas. PLWD in rural locations may face additional barriers to accessing services. The majority (72%) of PLWD were white and older people from other ethnic groups may have different experiences and needs. However, a previous systematic review of qualitative studies found that there were many similarities in the experiences of people with dementia and their family carers regardless of culture and context.[23] Our findings, therefore, should have resonance for the wider community of older people with dementia and comorbidity.

Implications of the findings

To our knowledge this is the first study to focus on research and practice in relation to comorbidity in dementia. Most research on multimorbidity has been concerned with its effect on prevalence and physical functioning and its measurement, with little research investigating patient and carer preferences and experiences, the effect on processes of care or what constitutes 'best care' for these patients.[22,59] Moreover, qualitative research on dementia to date has tended to focus on the experience of living with dementia as a single disease.[23] This study sets out current research and knowledge about the impact of comorbidities on people diagnosed with dementia and what is known about their experiences of health care. It highlights what experiences are common to PLWD and those with other complex health and social care needs. It also demonstrates how a diagnosis of dementia creates extra and different needs from those experienced by people with a long-term condition but without dementia. Based on these findings it is reasonable to argue that a service that is accessible and provides continuity of information and management for someone living with dementia and their carer is a service that could address the needs of all patients with a long-term condition and one that should be a benchmark of good practice.

Continuity of care

Our study supports previous research that relationship continuity and the personal characteristics of HCPs are important to older people with complex health needs[209,210] and their family carers.[48] We found that, for PLWD, relationship continuity can facilitate access to some services, for example a patient may not automatically be taken off a clinic list if they miss an appointment or clinicians may more easily assess a patient's progress. It has been argued that in some settings such as primary care there may be a trade-off between continuity and access,[211] although people with chronic and serious conditions may be willing to trade off delays in access to routine care against increased continuity.[46]

The estimated median survival time for people with a diagnosis of dementia in the UK is 4.5 years,[58] but this may be greater, particularly in those who are diagnosed younger.[127] Many PLWD will have comorbid health conditions and, as such, are likely to require management continuity that spans a number of years. Despite this, PLWD and their family carers often experienced poor management and informational

continuity. Of particular concern was that HCPs specialising in diabetes, stroke and VI were often unaware that someone had a diagnosis of dementia. In many cases our participants had a long-standing health condition before the development and diagnosis of dementia and this might explain why the diagnosis of dementia had not been transferred from one service to another. There may be a need for automated systems that trigger condition updates in clinics.

Access to care

It is well established that people with dementia are less likely than people without dementia to receive equivalent care for similar health conditions and experiences. Previous research has shown that PLWD may have poorer end-of-life care than those with conditions such as cancer.[162,212] There was evidence from the scoping review that people with dementia do not have the same access as those without dementia to treatment and monitoring for conditions such as VI and diabetes. This may be because people with dementia may be less likely to attend regular appointments or to notice or report relevant symptoms and they may be more reliant on carers to manage and facilitate appointments.[117] Our study supports the idea that people with dementia often lack candidacy and may be reliant on family carers to facilitate continuity and access. This clearly has implications for people with dementia who live alone or who do not have family support. Our study found that housebound patients and those who lived alone were a particular concern for GPs, who worried that they may be missing out on care. Although research suggests that people with dementia who live alone have an increased risk for unmet social, environmental, psychological and medical needs,[213] we were unable to identify examples of research or practice that indicated how this problem was being addressed by different services.

Access to health care has been defined as the 'degree of fit between the clients and the system' (p. 128).[63] For people with dementia the degree of fit may be poor because systems and the clinical environment do not meet their needs, leading to the exacerbation of symptoms and distress. There may be transferable learning from services for people with learning disability, who are another group who have problems with access and continuity.[214] The key difference, however, is that for PLWD there is a history of having been able to manage independently and for people with a learning disability there is a formal recognition of their need for advocacy and support in the navigation of health care.

Conditions such as diabetes or VI may not be recognised in people with dementia because their symptoms are misinterpreted, especially if the person with dementia is experiencing the behavioural and psychological symptoms associated with dementia.[215,216] For example, people with dementia who develop diabetes may appear to have a worsening of their dementia because the symptoms of diabetes, such as confusion because of elevated blood glucose or incontinence, are wrongly attributed to dementia.[112] Problems such as falling or not recognising objects may be misinterpreted as signs of dementia, meaning that HCPs fail to investigate the possibility that they are the result of some form of VI. This is a major issue as some interventions, for example cataract operations, have the potential to improve quality of life and physical functioning for someone with dementia.[217]

Clinicians may be more reluctant to investigate and treat VI in patients with dementia either because of the difficulties in securing patient co-operation or because treatments are considered inappropriate, or difficult to perform, in patients with dementia.[117] Clinicians in our study across the three conditions expressed concerns about compliance, consent and the appropriateness of treatment in older people with dementia, especially for those with multimorbidity or more advanced dementia. For conditions such as VI it would be better to treat people with dementia earlier rather than later and there may be an argument for fast-tracking people with dementia for treatments such as surgery for cataracts. Our study also suggests that there is a need for further research that addresses how rehabilitation might be delivered to people with dementia who have had a stroke, for example including family carers[218] or adjusting rehabilitation strategies for people with dementia.

Initiatives to improve continuity and access for people with dementia and comorbidities

Hospital-based initiatives

In the scoping review (see *Chapter 4*) we considered some of the initiatives that have been developed with the aim of improving care for older people with dementia in acute hospitals. This includes liaison psychiatric services[113] and specialist units that combine medical and mental health care for older people.[109] As yet, it is not clear if specialist units lead to better outcomes for PLWD or if these are the most appropriate care environments for PLWD who have acute care needs. For example, a person with dementia being admitted after a stroke may need to be in an acute stroke unit, or a person with dementia undergoing surgery for cataracts may need to be on an ophthalmology ward. The challenge from this study's findings is how to make all staff practice and health-care environments appropriate for PLWD as well as investing in specialist dementia services to ensure that the behavioural and psychological symptoms of dementia are addressed within mainstream health-care provision.

Dementia-friendly environments

Recent years have seen a growing interest in initiatives designed to make health-care environments more dementia friendly. The UK government recently spent £50M on 116 projects aimed at improving environments for people with dementia in NHS and local authority settings.[219] There are a variety of tools and resources designed to improve the identification of people with dementia in busy acute environments and make health-care settings dementia friendly (e.g. the Butterfly Scheme,[220] the Shining the Spotlight programme,[221] the Pabulum Blue Book,[222] 'This is me', Carer's Passport,[223,224] trust dementia portals). However, there have been few evaluations of their effectiveness and we found no evidence to suggest that these initiatives were being used in specialist services for diabetes, stroke or VI.

Ideas on person-centred care[49,54,225] have had a considerable impact on approaches to the care of people with dementia in health-care settings. However, despite policy support for person-centred approaches to care for people with cognitive impairment,[55,226] health services have struggled to deliver it.[227] The aim of initiatives such as 'Getting to know me' [see www.scottishcare.org/news/getting-to-know-me-dementia-resource-launched/ (accessed 5 January 2016)] or 'This is me' is to encourage health and social care professionals to see the person with dementia as an individual and deliver person-centred care that is tailored specifically to the person's needs.[228] Although a number of HCPs in our study were aware of the 'This is me' tool, very few PLWD and their carers were actively using it. Moreover, dementia specialists reported that they were often not properly filled in. It was not clear from this study why such tools were not being used and more work is needed on their evaluation and promotion.

Holistic care

One approach that has been suggested for delivering holistic, integrated care to PLWD is collaborative care or case management.[229] In this approach a care/case manager co-ordinates care between professionals, liaises between primary and secondary care and utilises evidence-based care pathways to address both physical and psychosocial needs. Despite positive benefits for both PLWD and their carers in some individual trials,[230] recent systematic reviews have found little clinical effectiveness or cost-effectiveness evidence to support widespread case management implementation beyond some quality-of-life benefits.[186,188,189] A recent pilot trial to evaluate the feasibility of case management in the UK struggled to successfully implement a nurse/social worker case manager intervention despite considerable support for this care approach from both patients and primary care teams.[190] However, this was largely because of the study coinciding with considerable organisational change within primary care.[231] In view of our findings of increasing physical comorbidity in people with dementia, such a model may require further testing as similar European health-care systems have managed successful integration into existing care.[192]

Workforce development

In the UK, most chronic illness care of PLWD will be provided by GPs and their primary care teams. However, the 2007 National Audit Office report on improving services for PLWD[232] found that, in its national GP survey, less than one-third of GPs felt that they had sufficient training to provide care for PLWD. Despite our rapidly ageing society, even current generations of doctors are not being adequately prepared to meet patient population needs, as medical student surveys have shown.[233] A recent recommendation from the Royal College of General Practitioners[234] that GP training be extended to 4 years, to specifically include care of older people and management of multimorbidity, has not yet been implemented.

Despite a national policy push on dementia care through a national strategy[25] and the Prime Minister's dementia challenge,[235] it would seem that we are still not adequately training our key community-based HCPs to meet societal need.[206] HCPs in our study consistently reported feeling underprepared to care for people with dementia. They raised concerns about generic issues such as behavioural and psychological symptoms but also condition-specific concerns, for example the best strategies for performing eye tests for PLWD, the best medication regimens for people with dementia and diabetes and approaches to rehabilitation for people with dementia who had had a stroke. This is consistent with a recent survey of dementia champions which suggests that dementia training should be specific to the clinical setting.[204]

An assessment of dementia care between 2009 and 2014[206] suggests that, although training initiatives such as that delivered via Health Education England[236] and the Royal Colleges have led to improvements in care, more work needs to be carried out to improve training and education curricula. An audit of training in Hertfordshire and Bedfordshire found that uptake of dementia training may be greater among more junior staff, who have the most patient contact but who may lack authority to change practices.[204] Senior clinicians in our study showed an awareness of the needs of PLWD but many of the suggestions that they made for improving care for PLWD were aspirational rather than routinely implemented in current practice. It would appear that initiatives to increase staff awareness of dementia need to be further developed so that the needs of someone with a comorbid condition and dementia can be routinely accommodated into assessment, planning and review of care across all services.

The management of risk

There is a great deal of literature on the management of risk in dementia, particularly for those who are living independently at home.[237] For people with a comorbid condition such as diabetes, VI or stroke, the risk is even greater. Older people with diabetes and dementia are at greater risk of hypoglycaemia than older people without dementia.[238] Family carers of people with dementia and diabetes reported a number of ways in which dementia impacted on blood sugar control, resulting in hypoglycaemia and, in some instances, hospitalisation. This included family members with dementia forgetting that they had already eaten and eating twice or forgetting to eat at all. Carers also reported instances in which family members had forgotten to take medication or had taken medication (including insulin) more than once. The management of risk was a common theme in HCPs' narratives, generally expressed in the context of uncertainty about what would be best for the patient, the family carer and the service. A more structured approach to the assessment of risk is needed that can help professionals focus on the PLWD and consider systematically the risk–benefit balance of different treatment options. The study findings suggested that at the moment this is very much at the discretion of the individual practitioner.

Carer inclusion and support

The CFAS analysis showed an increase in use of hospital services and unpaid care by people with dementia and a comorbid condition over the past decade. Analysis within CFAS II only showed that unpaid care was used substantially more by those with dementia and a target health condition than by those with the health condition alone. Previous analysis in CFAS has shown that fewer people are moving into care settings,[164] which could, in turn, influence the use of unpaid care. It is well documented that those with dementia and their carers have difficulties with accessing the support that they need day to day.[239,240]

This lack of appropriate community-based support could mean that individuals access health services at only their greatest times of need or crisis and may explain the increased hospital use. Some of the greatest barriers reported in terms of access to day-to-day services were the lack of communication between health and social care and a lack of formal training on dementia care available to those in community-based day-to-day services. Suggestions on how to improve access to day-to-day services included education and training on the impact of dementia on the management of other health conditions.[241]

The challenges that carers of PLWD face are well documented.[23,242] Family caregivers of people who have dementia and other health conditions face additional challenges in managing both conditions and dealing with the impact of the accompanying behavioural and psychological symptoms of dementia on care routines.[102] Our study suggests that care pathways need to recognise the contribution of family members and, when available, incorporate their contribution in the care of PLWD. Pathways should include appropriate support for carers that addresses the possibility that carers do not want or cannot absorb the extra responsibilities of caring for someone with a condition such as diabetes. This support might need to focus on times of transition, for example from hospital to home after a stroke, or on the transition from self-management to dependency for a person with a long-term condition such as diabetes. Although services such as those provided by Admiral Nurses focus on the support of carers, there is relatively little understanding of which models of support are likely to be most effective or how they should be evaluated.[48] Moreover, it is not clear whether or not such services would be able to provide the appropriate support for carers of PLWD and a physical comorbidity such as diabetes or VI.

There is an increasing recognition of the importance of strengthening relationships between patients, carers and professionals.[243,244] In the USA the Institute for Patient- and Family-Centered Care[245] set out four core concepts of patient- and family-centred care: dignity, respect, information sharing, and participation and collaboration. Its approach is based on the premise that families are crucial allies for quality and safety and that the individuals most dependent on health care, such as the very old and those with chronic conditions, are also those who are most dependent on families.

In the UK the triangle of care model[50] focuses on carer inclusion and support. Originally developed for mental health service users the model has been adapted to meet the needs of carers of people with dementia in acute hospital. The model (*Box 9*) requires that staff are willing to collaborate and engage with PLWD and their family carers and involve the carers in decisions about the care and treatment of their relative. Although HCPs in our study acknowledged the importance of family carers, they did not generally articulate this in a way that addressed the clear expectations outlined in the triangle of care model. The model requires further testing and development, specifically on how it is implemented and how it can address issues such as confidentiality, the involvement of multiple carers or divergence of opinion between the PLWD and the carer. It also cannot address the needs of someone whose carer network involves loose ties or shifting patterns of unpaid support.

BOX 9 The six key standards of the triangle of care model

1. Carers and the essential role that they play are identified at first contact or as soon as possible thereafter.
2. Staff are 'carer aware' and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing information are in place.
4. Defined post(s) responsible for carers are in place.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
6. A range of carer support services is available.

Conclusions

Significant numbers of PLWD have comorbid conditions such as stroke, diabetes and VI and many of them have multimorbidities. The presence of dementia complicates the delivery of health care and magnifies the known difficulties that people with long-term conditions experience when navigating health and social care. The situation is further complicated as some people will develop comorbidity in the presence of already diagnosed dementia and others will develop dementia subsequent to a comorbidity such as diabetes, stroke or VI.

The delivery of good-quality care to PLWD demands a particularly high standard of care across multiple domains, including communication, multidisciplinary care, clinical decision-making and engagement with families and carers. Effective care for older patients with dementia will help set a standard of care of universal relevance to vulnerable adults.[246] Good care for PLWD and comorbidity may vary according to the type of condition(s) that they have. However, key elements include the PLWD and the family carer at the centre, flexibility around processes, good communication between services, ensuring that all services are aware when someone has a diagnosis of dementia and taking into account the impact of a diagnosis of dementia on pre-existing conditions, and incorporating this into guidelines and care planning.

The role of family carers in managing health-care conditions of PLWD and their contribution in facilitating continuity and access to care are indisputable. It is important, therefore, that HCPs conceptualise the provision of care for people with dementia and a comorbidity as a complex phenomenon that affects not just individuals but also dyads and families. The challenges of being a carer have been exhaustively documented, and legislation and staff training to ensure that carers are recognised and supported has been in place for some time. What is not so well understood is how to involve and support family carers at different stages of the dementia trajectory.

People with dementia may have poorer access to services than people with the same comorbidities but without dementia. There appears to be a number of reasons for this. One reason is a poor fit with current pathways and services. Despite an increasing range of initiatives to make health-care environments more ‘dementia friendly’, it is clear that many health-care environments do not meet the needs of PLWD and their family carers and the impact of these initiatives on patient and carer outcomes is unclear. Furthermore, we found no evidence to suggest that they are being widely used in clinical environments for conditions such as diabetes, stroke and VI. Access to care is also affected by the way that HCPs balance the risks and benefits of treatments for PLWD. Clearly, HCPs will sometimes have legitimate concerns about the risks of interventions or treatments for PLWD but it has been suggested that the construction and definition of risk by health and social care professionals may be different from the perceptions of PLWD and their family carers.[247] Moreover, there is a need to address negative perceptions about PLWD that may impact on how they are perceived and treated.[248]

There is already a great deal of descriptive work on the experiences of PLWD and their family carers.[23] This study adds to that by providing information about the experiences of people with dementia and comorbid health conditions, the views of HCPs caring for them and how dementia impacts on the management of comorbid health conditions in PLWD. It also provides data on the prevalence of comorbidities and service use among people with dementia and comorbidities. We provide a number of ideas/recommendations for practice and research, some of which are generic to people with dementia and comorbidity and some of which are condition specific. We suggest that future work needs to focus on the development and evaluation of interventions rather than on further descriptive studies. PLWD should be included in the debate about the management of comorbidities in older populations and there needs to be greater consideration given to including them in studies that focus on age-related health-care issues.

Implications for practice

- The evidence suggests that the use of models such as the triangle of care model may be helpful in ensuring that the input of family carers is properly recognised. This should include the identification of family carers, appropriate training in carer engagement for staff, and policy and practice protocols regarding confidentiality and information sharing.
- Our study suggests that systems for booking appointments need to be made more 'dementia friendly', for example not booking appointments by telephone, sending reminders and including nominated family carers in all correspondence (this may not be the primary carer if the primary carer is a spouse with memory problems).
- The evidence suggests that staff at all levels, including more senior staff, need appropriate training on dementia. Some training may need to be tailored to specific conditions, for example identifying the best strategies for the rehabilitation of PLWD who have had a stroke.
- Professional bodies for HCPs may need to consider how the current provision of dementia training on undergraduate programmes can be improved.
- HCPs in specialist areas are often unaware that someone has dementia. Our evidence suggests that a diagnosis of dementia should be flagged up on medical/electronic records. This should include systems for automatic updates of a dementia diagnosis to be transferred to health-care services that the PLWD is already attending.
- PLWD who live alone or who do not have family support may be particularly disadvantaged and may need additional help to navigate systems and access care.
- PLWD are likely to benefit from longer appointments, both in primary and in secondary care.
- PLWD may need a suitably trained staff member to help them navigate clinic environments; they may also benefit from assessments being carried out by specialists in their own home or at their local GP surgery.
- HCPs caring for people with cognitive impairment and long-term conditions such as diabetes need to regularly assess patients' ability to self-manage and identify when they may need additional support.
- Evidence suggests that there is a need for better integration of physical and mental health-care systems, that is, old-age psychiatry teams and geriatric teams working together and community-based geriatric teams having specialist mental health as an integral part of the team.
- Our study suggests that, for people with dementia and diabetes, who need support from health and social care, there is a need to link medication and monitoring of diabetes with the provision of meals.
- The evidence suggests that people with dementia and diabetes may not be undergoing regular eye and foot checks.

Suggestions for future research

Potential areas for future research identified by the study include the following:

- What makes a 'good' dementia QOF, for example what components should be routinely included and should they include physical health checks?
- What is the impact of providing PLWD and their family carers with support, either from a professional or from a trained lay person, to help navigate health-care systems?
- What are the impacts on PLWD, their family carers and other HCPs of specialist dementia nurses, such as Admiral Nurses, working in hospital and community settings?
- Is a collaborative care approach, with a case manager to provide integrated physical and psychological care, an effective approach to the provision of dementia care for people with dementia and comorbidities and which population of PLWD are most likely to benefit from case management and at what stage?
- What is the impact of dementia case finding for older people with stroke, diabetes and VI, for example the use of case finding on admission to hospital or at the first clinic appointment?
- What is the impact of expanding the 'This is me' document to include health-related information?
- How can patients, carers and HCPs be encouraged to use the 'This is me' document?

- What interventions can be used to improve medication management in PLWD, for example what is the impact of pharmacists carrying out short cognitive screening on older patients with multiple medications?
- Diabetes – how can HCPs caring for people with long-term conditions and dementia be helped to recognise when a person is no longer able to self-manage?
- Diabetes – what is the impact of self-management interventions for diabetes that involve family carers of adults with diabetes and cognitive impairment?
- Diabetes – what is the impact of personalised glycaemic targets for PLWD on outcomes such as hypoglycaemic attacks, hospital admissions and falls?
- Stroke – what are the most effective and cost-effective approaches to stroke rehabilitation for people with dementia?
- VI – how can tests for VI be made appropriate or adapted for PLWD?
- VI – is it possible to fast track PLWD for treatment such as surgery for cataracts and if so what are the impacts of this?
- VI – how can ophthalmology clinics and other health-care environments be made to be more dementia friendly so that they are suitable for people with VI or sight loss as well as dementias?

Acknowledgements

The authors would like to thank the following:

- Dr Simon Conroy, Dr Catherine Dennison, Professor Murna Downs, Heather Maggs, Dr James Pickett and Dr Jill Rasmussen – members of the Project Advisory Group
- Dr Vina Mayor, Marion Cowe, Dr Paul Millac and Diane Munday – members of the Public Involvement in Research Group at the University of Hertfordshire who acted as the User Reference Group for the study and attended the consensus conference
- HCPs who took part in our interviews and focus groups and those who attended the consensus conference
- Reinhard Wentz (Information Scientist) for advice on the search strategy for the scoping review.

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by the authors in this publication are those of the authors and do not necessarily reflect those of the NHS, NIHR, NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), Health Services and Delivery Research programme or Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, the NHS, the NIHR, the Medical Research Council (MRC), the Central Commissioning Facility, NETSCC, the Health Services and Delivery Research programme or the Department of Health.

Contributions of authors

Frances Bunn, **Claire Goodman**, **Louise Robinson**, **Greta Rait**, **Sam Norton**, **Johan Schoeman and Carol Brayne** wrote the protocol. **Frances Bunn**, **Anne-Marie Burn** and **Marie Poole** undertook the analysis of the qualitative data. **Sam Norton** and **Holly Bennett** undertook the analysis and writing up of the CFAS data. **Carol Brayne** is the principal investigator on the CFAS study that generated the data for analysis. **Frances Bunn** and **Anne-Marie Burn** wrote the first draft of the report. **Claire Goodman**, **Louise Robinson**, **Greta Rait**, **Sam Norton**, **Holly Bennett** and **Carol Brayne** contributed to the writing of the report.

All authors critically reviewed the manuscript and agreed the final version.

Publications

Bunn F, Burn A-M, Goodman C, Rait G, Norton S, Robinson L, *et al.* Comorbidity and dementia: a scoping review of the literature. *BMC Med* 2014;**12**:192.

Bunn F, Goodman C, Burn A-M. Multimorbidity and frailty in people with dementia. *Nurs Standard* 2015;**30**:45–50.

Data sharing statement

Data from the MRC CFAS studies are available on request. Information on the data available and the process for requesting MRC CFAS data are provided at www.cfas.ac.uk (accessed 9 December 2015). Other data can be obtained from the corresponding author subject to safeguarding the confidentiality and anonymity of participants.

References

1. Doraiswamy PM, Leon J, Cummings JL, Marin D, Neumann PJ. Prevalence and impact of medical comorbidity in Alzheimer's disease. *J Gerontol A Biol Sci Med Sci* 2002;**57**:M173–7. http://dx.doi.org/10.1093/gerona/57.3.M173
2. Schubert CC, Boustani M, Callahan CM, Perkins AJ, Carney CP, Fox C, *et al.* Comorbidity profile of dementia patients in primary care: are they sicker? *J Am Geriatr Soc* 2006;**54**:104–9. http://dx.doi.org/10.1111/j.1532-5415.2005.00543.x
3. Banerjee S. Multimorbidity – older adults need health care that can count past one. *Lancet* 2014;**385**:587–9. http://dx.doi.org/10.1016/S0140-6736(14)61596-8
4. Guthrie B, Payne K, Alderson P, McMurdo ME, Mercer SW. Adapting clinical guidelines to take account of multimorbidity. *BMJ* 2012;**345**:e6341. http://dx.doi.org/10.1136/bmj.e6341
5. Alzheimer's Disease International. *World Alzheimer's Report 2010. The Global Economic Impact of Dementia*. London: Alzheimer's Disease International; 2010. URL: www.alz.co.uk/research/files/WorldAlzheimerReport2010.pdf (accessed 28 May 2015).
6. Luengo-Fernandez R, Leal J, Gray A. *Alzheimer's Research Trust Dementia 2010: The Economic Burden of Dementia and Associated Research Funding in the United Kingdom*. Health Economics Research Centre; 2010. URL: www.alzheimersresearchuk.org/wp-content/uploads/2015/01/Dementia2010Full.pdf (accessed 28 May 2015).
7. Alzheimer's Society. *Summary of Key Findings: a Report to the Alzheimer's Society on the Prevalence and Economic Cost of Dementia in the UK Produced by King's College London and London School of Economics*. London: Alzheimer's Society; 2007. URL: www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1 (accessed 28 May 2015).
8. Alzheimer's Society. *Dementia UK Update*. London: Alzheimer's Society; 2014. URL: www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2323 (accessed 28 May 2015).
9. Royal College of Psychiatrists. *National Audit of Dementia Care in General Hospitals 2012–13: Second Round Audit Report and Update*. London: Healthcare Quality Improvement Partnership; 2013. URL: www.rcpsych.ac.uk/pdf/NAD%20NATIONAL%20REPORT%202013%20reports%20page.pdf (accessed 28 May 2015).
10. Valderas JM, Starfield B, Sibbald B, Salisbury C, Roland M. Defining comorbidity: implications for understanding health and health services. *Ann Fam Med* 2009;**7**:357–63. http://dx.doi.org/10.1370/afm.983
11. Kuo T-C, Zhao Y, Weir S, Kramer MS, Ash AS. Implications of comorbidity on costs for patients with Alzheimer disease. *Med Care* 2008;**46**:839–46. http://dx.doi.org/10.1097/MLR.0b013e318178940b
12. Heun R, Schoepf D, Potluri R, Natalwala A. Alzheimer's disease and co-morbidity: increased prevalence and possible risk factors of excess mortality in a naturalistic 7-year follow-up. *Eur Psychiatry* 2013;**28**:40–8. http://dx.doi.org/10.1016/j.eurpsy.2011.06.001
13. Leon J, Cheng CK, Neumann PJ. Alzheimer's disease care: costs and potential savings. *Health Aff (Millwood)* 1998;**17**:206–16. http://dx.doi.org/10.1377/hlthaff.17.6.206
14. Poblador-Plou B, Calderon-Larranaga A, Marta-Moreno J, Hancco-Saavedra J, Sicras-Mainar A, Soljak M, *et al.* Comorbidity of dementia: a cross-sectional study of primary care older patients. *BMC Psychiatry* 2014;**14**:84. http://dx.doi.org/10.1186/1471-244X-14-84

15. Richards M, Brayne C. What do we mean by Alzheimer's disease? *BMJ* 2010;**341**:c4670. http://dx.doi.org/10.1136/bmj.c4670

16. Norton S, Matthews FE, Barnes DE, Yaffe K, Brayne C. Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *Lancet Neurol* 2014;**13**:788–94. http://dx.doi.org/10.1016/S1474-4422(14)70136-X

17. Barnes DE, Yaffe K. The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurol* 2011;**10**:819–28. http://dx.doi.org/10.1016/S1474-4422(11)70072-2

18. Biessels GJ, Staekenborg S, Brunner E, Brayne C, Scheltens P. Risk of dementia in diabetes mellitus: a systematic review. *Lancet Neurol* 2006;**5**:64–74. http://dx.doi.org/10.1016/S1474-4422(05)70284-2

19. Whitmer RA, Karter AJ, Yaffe K, Quesenberry CP, Selby JV. Hypoglycemic episodes and risk of dementia in older patients with type 2 diabetes mellitus. *JAMA* 2009;**301**:1565–72. http://dx.doi.org/10.1001/jama.2009.460

20. Hewitt J, Smeeth L, Chaturvedi N, Bulpitt CJ, Fletcher AE. Self management and patient understanding of diabetes in the older person. *Diabet Med* 2010;**28**:117–22. http://dx.doi.org/10.1111/j.1464-5491.2010.03142.x

21. Sinclair AJ, Girling AJ, Bayer AJ. Cognitive dysfunction in older subjects with diabetes mellitus: impact on diabetes self-management and use of care services. *Diabetes Res Clin Pract* 2000;**50**:203–12. http://dx.doi.org/10.1016/S0168-8227(00)00195-9

22. Fortin M, Soubhi H, Hudon C, Bayliss EA, Van Den Akker M. Multimorbidity's many challenges. *BMJ* 2007;**334**:1016–17. http://dx.doi.org/10.1136/bmj.39201.463819.2C

23. Bunn F, Goodman C, Sworn K, Rait G, Brayne C, Robinson L, *et al.* Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLOS Med* 2012;**9**:e1001331. http://dx.doi.org/10.1371/journal.pmed.1001331

24. Iliffe S, Manthorpe J, Eden A. Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study. *Fam Pract* 2003;**20**:376–81. http://dx.doi.org/10.1093/fampra/cmg407

25. Department of Health. *National Dementia Strategy*. London: HMSO; 2009. URL: www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf (accessed 28 May 2015).

26. Royal College of Psychiatrists. *Report of the National Audit of Dementia Care in General Hospitals*. London: Healthcare Quality Improvement Partnership; 2011. URL: www.rcpsych.ac.uk/pdf/NATIONAL%20REPORT%20-%20Full%20Report%201201122.pdf (accessed 28 May 2015).

27. Royal College of Psychiatrists. *Who Cares Wins, Improving the Outcome for Older People Admitted to the General Hospital. Guidelines for the Development of Liaison Mental Health Services for Older People*. London: Royal College of Psychiatrists; 2005. URL: www.rcpsych.ac.uk/PDF/WhoCaresWins.pdf (accessed 28 May 2015).

28. Department of Health. *Prime Minister's Challenge on Dementia: Delivering Major Improvements in Dementia Care and Research by 2015*. London: Department of Health; 2012. URL: www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf (accessed 28 May 2015).

29. Ministerial Advisory Group on Dementia Research. *Final Report from the MAGDR Subgroup 1 on Priority Topics in Dementia Research, February 2011*. London: Medical Research Council; 2011. URL: www.gov.uk/government/uploads/system/uploads/attachment_data/file/215558/dh_127904.pdf (accessed 28 May 2015).

30. Wallace E, Salisbury C, Guthrie B, Lewis C, Fahey T, Smith SM. Managing patients with multimorbidity in primary care. *BMJ* 2015;**350**:h176. http://dx.doi.org/10.1136/bmj.h176

31. Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. *BMJ* 2003;**327**:1219–21. http://dx.doi.org/10.1136/bmj.327.7425.1219

32. Fulop N, Allen P. *National Listening Exercise: Report of the Findings*. London: NHS Service Delivery and Organisation; 2000. URL: www.netscc.ac.uk/hsdr/files/adhoc/listeningexercise.pdf (accessed 28 May 2015).

33. Parker G, Corden A, Heaton J. *Synthesis and Conceptual Analysis of the SDO Programme's Research on Continuity of Care. Report for the National Institute for Health Research Service Delivery and Organisation Programme*. SDO project (08/1813/248). Southampton: National Institute for Health Research Service Delivery and Organisation programme; 2009. URL: www.nets.nihr.ac.uk/__data/assets/pdf_file/0006/64545/FR-08-1813-248.pdf (accessed 28 May 2015).

34. Gulliford M, Figueroa-Munoz J, Morgan M, Hughes D, Gibson B, Beech R, *et al.* What does 'access to health care' mean? *J Health Serv Res Policy* 2002;**7**:186–8. http://dx.doi.org/10.1258/135581902760082517

35. Van Walraven C, Oake N, Jennings A, Forster AJ. The association between continuity of care and outcomes: a systematic and critical review. *J Eval Clin Pract* 2010;**16**:947–56. http://dx.doi.org/10.1111/j.1365-2753.2009.01235.x

36. Björkelund C, Maun A, Murante AM, Hoffmann K, De Maeseneer J, Farkas-Pall Z. Impact of continuity on quality of primary care: from the perspective of citizens' preferences and multimorbidity – position paper of the European Forum for Primary Care. *Qual Prim Care* 2013;**21**:193–204.

37. Salisbury C, Goodall S, Montgomery AA, Pickin DM, Edwards S, Sampson F, *et al.* Does advanced access improve access to primary health care? Questionnaire survey of patients. *Br J Gen Pract* 2007;**57**:615–21.

38. Nutting PA. Continuity of primary care: to whom does it matter and when? *Ann Fam Med* 2003;**1**:149–55. http://dx.doi.org/10.1370/afm.63

39. Pratt R, Clare L, Kirchner V. 'It's like a revolving door syndrome': professional perspectives on models of access to services for people with early-stage dementia. *Aging Ment Health* 2006;**10**:55–62. http://dx.doi.org/10.1080/13607860500307530

40. Freeman GK, Woloshynowych M, Baker R, Boulton M, Guthrie B, Car J, *et al. Continuity of Care 2006: What Have We Learned since 2000 and What Are Policy Imperatives Now*. London: National Coordinating Center for NHS Service Delivery and Organisation R&D; 2007. URL: www.hpm.org/Downloads/Bellagio/Articles/Continuity/138-final-report.pdf (accessed 28 May 2015).

41. Guthrie B, Saultz JW, Freeman GK, Haggerty JL. Continuity of care matters. *BMJ* 2008;**337**:a867 http://dx.doi.org/10.1136/bmj.a867

42. Goodman C. The organisational culture of nursing staff providing long-term dementia care is related to quality of care. *Evid Based Nurs* 2011;**14**:88–9. http://dx.doi.org/10.1136/ebn1158

43. Ellins J, Glasby J, Tanner D, McIver S, Davidson D, Littlechild R, *et al. Understanding and Improving Transitions of Older People: a User and Carer Centred Approach. Final Report*. Southampton: National Institute for Health Research Service Delivery and Organisation programme; 2012. URL: www.birmingham.ac.uk/documents/news/sdotransitions-report.pdf (accessed 28 May 2015).

44. Goodman C, Drennan V, Manthorpe J, Gage H, D. T, Shah D, *et al. A Study of the Effectiveness of Inter Professional Working for Community Dwelling Older People*. Southampton: National Institute for Health Research Service Delivery and Organisation programme; 2012. URL: www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1819-216_V01.pdf (accessed 28 May 2015).

45. Heaton J, Corden A, Parker G. 'Continuity of care': a critical interpretive synthesis of how the concept was elaborated by a national research programme. *Int J Integr Care* 2012;**12**:e12.

46. Parker G, Corden A, Heaton J. Experiences of and influences on continuity of care for service users and carers: synthesis of evidence from a research programme. *Health Soc Care Community* 2011;**19**:576–601. http://dx.doi.org/10.1111/j.1365-2524.2011.01001.x

47. Spenceley SM, Sedgwick N, Keenan J. Dementia care in the context of primary care reform: an integrative review. *Aging Ment Health* 2015;**19**:107–20. http://dx.doi.org/10.1080/13607863.2014.920301

48. Bunn F, Goodman C, Pinkney E, Drennan V. Specialist nursing and community support for the carers of people with dementia living at home: an evidence synthesis [published online ahead of print 16 February 2015]. *Health Soc Care Community* 2015. http://dx.doi.org/10.1111/hsc.12189.

49. Brooker D. *Person-Centred Dementia Care: Making Services Better*. London: Jessica Kingsley; 2007.

50. Hannan R, Thompson R, Worthington A, Rooney P. *The Triangle of Care. Carers Included: A Guide to Best Practice for Dementia Care*. London: Carers Trust; 2013. URL: https://professionals.carers.org/sites/default/files/the_triangle_of_care_carers_included_best_practice_in_dementia_care_-_final.pdf (accessed 25 November 2014).

51. Adams T, Gardiner P. Communication and interaction within dementia care triads: developing a theory for relationship-centred care. *Dementia* 2005;**4**:185–205. http://dx.doi.org/10.1177/1471301205051092

52. National Quality Forum. *National Voluntary Consensus Standards for Coordination of Care Across Episodes of Care and Care Transitions*. October 2012. URL: www.qualityforum.org/Projects/c-d/Care_Coordination_Endorsement_Maintenance/Care_Coordination_Endorsement_Maintenance.aspx (accessed 22 December 2015).

53. Department of Health. *Our NHS Our Future: NHS Next Stage Review – Interim Report*. London: Department of Health; 2007. URL: http://webarchive.nationalarchives.gov.uk/+/dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_079077 (accessed 8 December 2015).

54. Brooker D. What is person-centred care in dementia? *Rev Clin Gerontol* 2004;**13**:215–22. http://dx.doi.org/10.1017/S095925980400108X

55. Department of Health. *Living Well with Dementia: A National Dementia Strategy*. London: Department of Health; 2009. URL: www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy (accessed 28 May 2015).

56. Bodenheimer T. Coordinating care – a perilous journey through the health care system. *N Engl J Med* 2008;**358**:1064–71. http://dx.doi.org/10.1056/NEJMhpr0706165

57. Crooks VA, Agarwal G. What are the roles involved in establishing and maintaining informational continuity of care within family practice? A systematic review. *BMC Fam Pract* 2008;**9**:65. http://dx.doi.org/10.1186/1471-2296-9-65

58. Xie J, Brayne C, Matthews FE. Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *BMJ* 2008;**336**:258–62. http://dx.doi.org/10.1136/bmj.39433.616678.25

59. Bunn F, Burn A-M, Goodman C, Rait G, Norton S, Robinson L, *et al.* Comorbidity and dementia: a scoping review of the literature. *BMC Med* 2014;**12**:192. http://dx.doi.org/10.1186/s12916-014-0192-4

60. Kringos DS, Boerma WG, Hutchinson A, van der Zee J, Groenewegen PP. The breadth of primary care: a systematic literature review of its core dimensions. *BMC Health Serv Res* 2010;**10**:65. http://dx.doi.org/10.1186/1472-6963-10-65

61. Benett IJ. Access, continuity, or both. *Br J Gen Pract* 2014;**64**:388–9. http://dx.doi.org/10.3399/bjgp14X680845

62. Gulliford M. Modernizing concepts of access and equity. *Health Econ Policy Law* 2009;**4**:223–30. http://dx.doi.org/10.1017/S1744133109004940

63. Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. *Med Care* 1981;**19**:127–40. http://dx.doi.org/10.1097/00005650-198102000-00001

64. Gulliford M, Morgan M. *Access to Health Care*. London: Routledge; 2013.

65. McIntyre D, Thiede M, Birch S. Access as a policy-relevant concept in low- and middle-income countries. *Health Econ Policy Law* 2009;**4**:179–93. http://dx.doi.org/10.1017/S1744133109004836

66. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, *et al.* Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Med Res Methodol* 2006;**6**:35. http://dx.doi.org/10.1186/1471-2288-6-35

67. Mackenzie M, Conway E, Hastings A, Munro M, O'Donnell C. Is 'candidacy' a useful concept for understanding journeys through public services? A critical interpretive literature synthesis. *Soc Policy Adm* 2013;**47**:806–25. http://dx.doi.org/10.1111/j.1467-9515.2012.00864.x

68. Fagot-Campagna A, Bourdel-Marchasson I, Simon D. Burden of diabetes in an aging population: prevalence, incidence, mortality, characteristics and quality of care. *Diabetes Metab* 2005;**31**:5S35–52.

69. Pendlebury S, Rothwell P. Prevalence, incidence, and factors associated with pre-stroke and post-stroke dementia: a systematic review and meta-analysis. *Lancet Neurol* 2009;**8**:1006–18. http://dx.doi.org/10.1016/S1474-4422(09)70236-4

70. Cheng G, Huang C, Deng H, Wang H. Diabetes as a risk factor for dementia and mild cognitive impairment: a meta-analysis of longitudinal studies. *Intern Med J* 2012;**42**:484–91. http://dx.doi.org/10.1111/j.1445-5994.2012.02758.x

71. Collerton J, Davies K, Jagger C, Kingston A, Bond J, Eccles MP, *et al.* Health and disease in 85 year olds: baseline findings from the Newcastle 85+ cohort study. *BMJ* 2009;**339**:b4904. http://dx.doi.org/10.1136/bmj.b4904

72. Lawrence V, Murray J, Ffytche D, Banerjee S. Out of sight, out of mind: a qualitative study of visual impairment and dementia from three perspectives. *Int Psychogeriatr* 2009;**21**:511–18. http://dx.doi.org/10.1017/S1041610209008424

73. Trigg R, Jones R. *Dementia and Blindness. Research findings no. 6*. London: Thomas Pocklington Trust; 2005.

74. McKeefry D, Bartlett R. *Improving Vision and Eye Health Care to People With Dementia. Research discussion paper no. 8*. London: Thomas Pocklington Trust; 2010.

75. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;**8**:19–32. http://dx.doi.org/10.1080/1364557032000119616

76. Levac D, Colquhoun H, O'Brien K. Scoping studies: advancing the methodology. *Implement Sci* 2010;**5**:1–9. http://dx.doi.org/10.1186/1748-5908-5-69

77. Rumrill PD, Fitzgerald SM, Merchant WR. Using scoping literature reviews as a means of understanding and interpreting existing literature. *Work* 2010;**35**:399–404. http://dx.doi.org/10.3233/WOR-2010-0998

78. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J* 2009;**26**:91–108. http://dx.doi.org/10.1111/j.1471-1842.2009.00848.x

79. Bunn F, Goodman C, Brayne C, Norton S, Rait G, Robinson L, *et al. Comorbidity and Dementia: Improving Healthcare for People with Dementia (CoDem)*. Southampton: National Institute for Health Research Health Services and Delivery Research programme; 2012. URL: www.nets.nihr.ac.uk/projects/hsdr/11101707 (accessed 28 May 2015).

80. Greenhalgh T, Peacock R. Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *BMJ* 2005;**331**:1064–5. http://dx.doi.org/10.1136/bmj.38636.593461.68

81. Copeland JRM, Dewey ME, Griffiths-Jones HM. A computerized psychiatric diagnostic system and case nomenclature for elderly subjects: GMS and AGECAT. *Psychol Med* 1986;**16**:89–99. http://dx.doi.org/10.1017/S0033291700057779

82. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition*. Washington, DC: American Psychiatric Association; 1994.

83. Folstein MF, Folstein SE, McHugh PR. 'Mini-mental state': a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;**12**:189–98. http://dx.doi.org/10.1016/0022-3956(75)90026-6

84. Coffey A, Atkinson P. *Making Sense of Qualitative Data: Complementary Research Strategies*. Thousand Oaks, CA: Sage Publications; 1996.

85. Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 2001;**322**:1115–17. http://dx.doi.org/10.1136/bmj.322.7294.1115

86. Delbecq A, Van de Ven A. A group process model for problem identification and program planning. *J Appl Behav Sci* 1971;**7**:466–92. http://dx.doi.org/10.1177/002188637100700404

87. Bartunek JM, Murninghan JK. The nominal group technique: expanding the basic procedure and underlying assumptions. *Group Organ Manag* 1984;**9**:417–32. http://dx.doi.org/10.1177/105960118400900307

88. Australian Commission on Safety and Quality in Health Care. *Evidence for the Safety and Quality Issues Associated with the Care of Patients with Cognitive Impairment in Acute Care Settings: a Rapid Review*. Sydney, NSW: Australian Commission on Safety and Quality in Health Care; 2013. URL: www.safetyandquality.gov.au/wp-content/uploads/2013/10/Rapid-Review_Evidence-for-the-safety-and-care-of-patients-with-cognitive-impairment-in-acute-care-settings.pdf (accessed 28 May 2015).

89. Allan K, Stapleton K, McLean F. *Dementia and Deafness: An Exploratory Study*. Stirling: Queensbury House Trust and the Scottish Executive; 2005.

90. Balfour J, O'Rourke N. Older adults with Alzheimer disease, comorbid arthritis and prescription of psychotropic medications. *Pain* 2003;**8**:198–204.

91. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 2012;**380**:37–43. http://dx.doi.org/10.1016/S0140-6736(12)60240-2

92. Bartlett A, Clarke B. An exploration of healthcare professionals' beliefs about caring for older people dying from cancer with a coincidental dementia. *Dementia* 2012;**11**:559–65. http://dx.doi.org/10.1177/1471301212437824

93. Bartlett R, McKeefry D. Rethinking the experiences and entitlements of people with dementia: taking vision into account. *J Care Serv Manag* 2011;**5**:105–14. http://dx.doi.org/10.1179/175016811X12966389037637

94. Bayer AJ, Johnston J, Sinclair AJ. Impact of dementia on diabetic care in the aged. *J R Soc Med* 1994;**87**:619–21.

95. Bruce DG, Casey GP, Grange V, Clarnette RC, Almeida OP, Foster JK, *et al.* Cognitive impairment, physical disability and depressive symptoms in older diabetic patients: the Fremantle Cognition in Diabetes Study. *Diabetes Res Clin Pract* 2003;**61**:59–67. http://dx.doi.org/10.1016/S0168-8227(03)00084-6

96. College of Optometrists. *Examining the Patient with Dementia or other Acquired Cognitive Impairment*. London: College of Optometrists; 2012.

97. Connolly A, Iliffe S, Gaehl E, Campbell S, Drake R, Morris J, *et al.* Quality of care provided to people with dementia: utilisation and quality of the annual dementia review in general practice. *Br J Gen Pract* 2012;**62**:e91–8. http://dx.doi.org/10.3399/bjgp12X625148

98. Curtis LH, Hammill BG, Qualls LG, Dimartino LD, Wang F, Schulman KA, *et al.* Treatment patterns for neovascular age-related macular degeneration: analysis of 284 380 Medicare beneficiaries. *Am J Opthalmol* 2012;**153**:1116–24. http://dx.doi.org/10.1016/j.ajo.2011.11.032

99. Dewing J, Dijk S. What is the current state of care for older people with dementia in general hospitals? A literature review [published online ahead of print 23 January 2014]. *Dementia (London)* 2014. http://dx.doi.org/10.1177/1471301213520172

100. Doucet J, Druesne L, Capet C, Gréboval E, Landrin I, Moirot P, *et al.* Risk factors and management of diabetes in elderly French patients. *Diabetes Metab* 2008;**34**:574–80. http://dx.doi.org/10.1016/j.diabet.2008.05.007

101. Feil D, Marmon T, Unutzer J. Cognitive impairment, chronic medical illness, and risk of mortality in an elderly cohort. *Am J Geriatr Psychiatry* 2003;**11**:551–60. http://dx.doi.org/10.1097/00019442-200309000-00010

102. Feil DG, Lukman R, Simon B, Walston A, Vickrey B. Impact of dementia on caring for patients' diabetes. *Aging Ment Health* 2011;**15**:894–903. http://dx.doi.org/10.1080/13607863.2011.569485

103. Feil DG, Pearman A, Victor T, Harwood D, Weinreb J, Kahle K, *et al.* The role of cognitive impairment and caregiver support in diabetes management of older outpatients. *Int J Psychiatry Med* 2009;**39**:199–214. http://dx.doi.org/10.2190/PM.39.2.h

104. Feil DG, Zhu CW, Sultzer DL. The relationship between cognitive impairment and diabetes self-management in a population-based community sample of older adults with type 2 diabetes. *J Behav Med* 2011;**35**:190–9. http://dx.doi.org/10.1007/s10865-011-9344-6

105. Formiga F, Fort I, Robles MJ, Riu S, Sabartes O, Barranco E, *et al.* Comorbidity and clinical features in elderly patients with dementia: differences according to dementia severity. *J Nutr Health Aging* 2009;**13**:423–7. http://dx.doi.org/10.1007/s12603-009-0078-x

106. George J, Adamson J, Woodford H. Joint geriatric and psychiatric wards: a review of the literature. *Age Ageing* 2011;**40**:543–8. http://dx.doi.org/10.1093/ageing/afr080

107. Gladman J, Porock D, Griffiths A, Clissett P, Harwood RH, Knight A, *et al. Care of Older People with Cognitive Impairment in General Hospitals*. Southampton: National Institute for Health Research Service Delivery and Organisation programme; 2012. URL: www.nets.nihr.ac.uk/__data/assets/pdf_file/0004/85072/FR-08-1809-227.pdf (accessed 28 May 2015).

108. Gold M, Lightfoot LA, Hnath-Chisolm T. Hearing loss in a memory disorders clinic: a specially vulnerable population. *Arch Neurol* 1996;**53**:922–8. http://dx.doi.org/10.1001/archneur.1996.00550090134019

109. Goldberg SE, Bradshaw LE, Kearney FC, Russell C, Whittamore KH, Foster PE, *et al.* Care in specialist medical and mental health unit compared with standard care for older people with cognitive impairment admitted to general hospital: randomised controlled trial (NIHR TEAM trial). *BMJ* 2013;**347**:f4132. http://dx.doi.org/10.1136/bmj.f4132

110. Guijarro R, San Roman CM, Gomez-Huelgas R, Villalobos A, Martin M, Guil M, *et al.* Impact of dementia on hospitalization. *Neuroepidemiology* 2010;**35**:101–8. http://dx.doi.org/10.1159/000311032

111. Hoffmann F, van den Bussche H, Wiese B, Schon G, Koller D, Eisele M, *et al.* Impact of geriatric comorbidity and polypharmacy on cholinesterase inhibitors prescribing in dementia. *BMC Psychiatry* 2011;**11**:190. http://dx.doi.org/10.1186/1471-244X-11-190

112. Hill J, Hicks D, James J, Vanterpool G, Gillespie C, Fox C, *et al. Diabetes and Dementia Guidance on Practical Management: Training, Research and Education For Nurses in Diabetes and Institute of Diabetes in Older People*. London: Institute of Diabetes for Older People and Trend UK; 2013.

113. Holmes J, Montana C, Powell G, Hewison J, House A, Mason J, *et al. Liaison Mental Health Services for Older People: a Literature Review, Service Mapping and In-Depth Evaluation of Service Models*. Southampton: National Institute for Health Research Service Delivery and Organisation programme; 2010.

114. Ishii K, Kabata T, Oshika T. The impact of cataract surgery on cognitive impairment and depressive mental status in elderly patients. *Am J Opthalmol* 2008;**146**:404–9. http://dx.doi.org/10.1016/j.ajo.2008.05.014

115. Jefferis JM, Mosimann UP, Clarke MP. Cataract and cognitive impairment: a review of the literature. *Br J Ophthalmol* 2011;**95**:17–23. http://dx.doi.org/10.1136/bjo.2009.165902

116. Jones R, Trigg R. *Dementia and Serious Sight Loss. Occasional paper*. London: Thomas Pocklington Trust; 2007.

117. Keenan TD, Goldacre R, Goldacre MJ. Associations between age-related macular degeneration, Alzheimer disease, and dementia: record linkage study of hospital admissions. *JAMA Ophthalmol* 2014;**132**:63–8. http://dx.doi.org/10.1001/jamaophthalmol.2013.5696

118. Löppönen MK, Isoaho RE, Räihä IJ, Vahlberg TJ, Loikas SM, Takala TI, *et al.* Undiagnosed diseases in patients with dementia – a potential target group for intervention. *Dement Geriatr Cogn Disord* 2004;**18**:321–9. http://dx.doi.org/10.1159/000080126

119. Lyketsos CG, Toone L, Tschanz J, Rabins PV, Steinberg M, Onyike CU, *et al.* Population-based study of medical comorbidity in early dementia and 'cognitive impairment, no dementia (CIND)': association with functional and cognitive impairment: the Cache County study. *Am J Geriatr Soc* 2005;**13**:656–64.

120. MacKenzie G, Ireland S, Moore S, Heinz I, Johnson R, Sahlas D. Tailored interventions to improve hypertension management after stroke or TIA – Phase II (Tims II). *Stroke* 2011;**42**:e599.

121. McCormick WC, Kukull WA, van Belle G, Bowen JD. Symptom patterns and comorbidity in the early stages of Alzheimer's disease. *J Am Geriatr Soc* 1994;**42**:517–21 http://dx.doi.org/10.1111/j.1532-5415.1994.tb04974.x

122. McKeefry D, Bartlett R. *The Development of Professional Guidelines for the Eye Examination of People with Dementia*. London: University of Bradford and Thomas Pocklington Trust; 2010.

123. Müther J, Abholz H-H, Wiese B, Fuchs A, Wollny A, Pentzek M. Are patients with dementia treated as well as patients without dementia for hypertension, diabetes, and hyperlipidaemia? *Br J Gen Pract* 2010;**60**:671–4. http://dx.doi.org/10.3399/bjgp10X515395

124. Parke B, Beaith A, Slater L, Clarke AM. Contextual factors influencing success or failure of emergency department interventions for cognitively impaired older people: a scoping and integrative review. *J Adv Nurs* 2011;**67**:1426–48. http://dx.doi.org/10.1111/j.1365-2648.2011.05611.x

125. Parke B, Hunter KF, Strain LA, Marck PB, Waugh EH, McClelland AJ. Facilitators and barriers to safe emergency department transitions for community dwelling older people with dementia and their caregivers: a social ecological study. *Int J Nurs Stud* 2013;**50**:1206–18. http://dx.doi.org/10.1016/j.ijnurstu.2012.11.005

126. Rabadi MH, Rabadi FM, Edelstein L, Peterson M. Cognitively impaired stroke patients do benefit from admission to an acute rehabilitation unit. *Arch Phys Med Rehabil* 2008;**89**:441–8. http://dx.doi.org/10.1016/j.apmr.2007.11.014

127. Rait G, Walters K, Bottomley C, Petersen I, Iliffe S, Nazareth I. Survival of people with clinical diagnosis of dementia in primary care: cohort study. *BMJ* 2010;**341**:c3584. http://dx.doi.org/10.1136/bmj.c3584

128. Sakurai H, Hanyu H, Kanetaka H, Sato T, Shimizu S, Hirao K, *et al.* Prevalence of coexisting diseases in patients with Alzheimer's disease. *Geriatr Gerontol Intl* 2010;**10**:216–17. http://dx.doi.org/10.1111/j.1447-0594.2010.00609.x

129. Saposnik G, Cote R, Rochon PA, Mamdani M, Liu Y, Raptis S, *et al.* Care and outcomes in patients with ischemic stroke with and without preexisting dementia. *Neurology* 2011;**77**:1664–73. http://dx.doi.org/10.1212/WNL.0b013e31823648f1

130. Shah R, Evans BJW, Edgar D. A survey of the availability of state-funded primary eye care in the UK for the very young and very old. *Ophthalmic Physiol Opt* 2007;**27**:473–81. http://dx.doi.org/10.1111/j.1475-1313.2007.00506.x

131. Sinclair AJ, Paolisso G, Castro M, Bourdel-Marchasson I, Gadsby R, Rodriguez Manas L. European Diabetes Working Party for Older People 2011 clinical guidelines for type 2 diabetes mellitus. Executive summary. *Diabetes Metab* 2011;**37**(Suppl. 3):S27–38. http://dx.doi.org/10.1016/S1262-3636(11)70962-4

132. Spencer K, Foster P, Whittamore KH, Goldberg SE, Harwood RH. Delivering dementia care differently – evaluating the differences and similarities between a specialist medical and mental health unit and standard acute care wards: a qualitative study of family carers' perceptions of quality of care. *BMJ Open* 2013;**3**:e004198. http://dx.doi.org/10.1136/bmjopen-2013-004198

133. Stenvall M, Berggren M, Lundström M, Gustafson Y, Olofsson B. A multidisciplinary intervention program improved the outcome after hip fracture for people with dementia – subgroup analyses of a randomized controlled trial. *Arch Gerontol Geriatr* 2012;**54**:e284–9. http://dx.doi.org/10.1016/j.archger.2011.08.013

134. Stephan B, Brayne C, Savva GM, Matthews FE. Occurrence of medical co-morbidity in mild cognitive impairment: implications for generalisation of MCI research. *Age Ageing* 2011;**40**:501–7. http://dx.doi.org/10.1093/ageing/afr057

135. Tadros G, Salama RA, Kingston P, Mustafa N, Johnson E, Pannell R, *et al.* Impact of an integrated rapid response psychiatric liaison team on quality improvement and cost savings: the Birmingham RAID model. *Psychiatrist* 2013;**37**:4–10. http://dx.doi.org/10.1192/pb.bp.111.037366

136. Thorpe CT, Thorpe JM, Kind AJH, Bartels CM, Everett CM, Smith MA. Receipt of monitoring of diabetes mellitus in older adults with comorbid dementia. *J Am Geriatr Soc* 2012;**60**:644–51. http://dx.doi.org/10.1111/j.1532-5415.2012.03907.x

137. Uhlmann R, Larson E, Koepsell T, Rees T, Duckert L. Visual impairment and cognitive dysfunction in Alzheimer's disease. *J Gen Intern Med* 1991;**6**:126–32. http://dx.doi.org/10.1007/BF02598307

138. Uhlmann RF, Larson EB, Rees TS, Koepsell TD, Duckert LG. Relationship of hearing impairment to dementia and cognitive dysfunction in older adults. *JAMA* 1989;**261**:1916–19. http://dx.doi.org/10.1001/jama.1989.03420130084028

139. Vitry AI, Roughead EE, Preiss AK, Ryan P, Ramsay EN, Gilbert AL, *et al.* Influence of comorbidities on therapeutic progression of diabetes treatment in Australian veterans: a cohort study. *PLOS ONE* 2010;**5**:e14024. http://dx.doi.org/10.1371/journal.pone.0014024

140. Whitson HE, Ansah D, Whitaker D, Potter G, Cousins SW, MacDonald H, *et al.* Prevalence and patterns of comorbid cognitive impairment in low vision rehabilitation for macular disease. *Arch Gerontol Geriatr* 2010;**50**:209–12. http://dx.doi.org/10.1016/j.archger.2009.03.010

141. Yochim BP, Mueller AE, Kane KD, Kahook MY. Prevalence of cognitive impairment, depression, and anxiety symptoms among older adults with glaucoma. *J Glaucoma* 2012;**21**:250–4. http://dx.doi.org/10.1097/IJG.0b013e3182071b7e

142. Zamrini E, Parrish JA, Parsons D, Harrell LE. Medical comorbidity in black and white patients with Alzheimer's disease. *South Med J* 2004;**97**:2–6. http://dx.doi.org/10.1097/01.SMJ.0000077061.01235.42

143. Zekry D, Herrmann FR, Grandjean R, Meynet M-P, Michel J-P, Gold G, *et al.* Demented versus non-demented very old inpatients: the same comorbidities but poorer functional and nutritional status. *Age Ageing* 2008;**37**:83–9. http://dx.doi.org/10.1093/ageing/afm132

144. Jara M, Zhang I, Tcherny-Lessenot S, Wanju S. Less or more cataracts in Alzheimer's disease. *Pharmacoepidemiol Drug Saf* 2011;**20**:S302–3.

145. Zhang Y, Vitry A, Roughead E, Ryan P, Gilbert A. Co-morbidity and the utilization of health care for Australian veterans with diabetes. *Diabet Med* 2010;**27**:65–71. http://dx.doi.org/10.1111/j.1464-5491.2009.02872.x

146. Pendlebury ST, Chen PJ, Bull L, Silver L, Mehta Z, Rothwell PM. Methodological factors in determining rates of dementia in transient ischemic attack and stroke: (I) impact of baseline selection bias. *Stroke* 2015;**46**:641–6. http://dx.doi.org/10.1161/STROKEAHA.114.008043

147. Sinclair AJ, Hillson R, Bayer AJ, National Expert Working Group. Diabetes and dementia in older people: a best clinical practice statement by a multidisciplinary National Expert Working Group. *Diabet Med* 2014;**31**:1024–31. http://dx.doi.org/10.1111/dme.12467

148. Poland F, Mapes S, Pinnock H, Katona C, Sorensen S, Fox C, *et al.* Perspectives of carers on medication management in dementia: lessons from collaboratively developing a research proposal. *BMC Res Notes* 2014;**7**:463. http://dx.doi.org/10.1186/1756-0500-7-463

149. Beishon LC, Harrison JK, Harwood RH, Robinson TG, Gladman JRF, Conroy SP. The evidence for treating hypertension in older people with dementia: a systematic review. *J Hum Hypertens* 2014;**28**:283–7. http://dx.doi.org/10.1038/jhh.2013.107

150. Murao K, Leys D, Jacquin A, Kitazono T, Bordet R, Bejot Y, *et al.* Thrombolytic therapy for stroke in patients with preexisting cognitive impairment. *Neurology* 2014;**82**:2048–54. http://dx.doi.org/10.1212/WNL.0000000000000493

151. Alshekhlee A, Li CC, Chuang SY, Vora N, Edgell RC, Kitchener JM, *et al.* Does dementia increase risk of thrombolysis?: a case–control study. *Neurology* 2011;**76**:1575–80. http://dx.doi.org/10.1212/WNL.0b013e3182190d37

152. Shamy MC, Jaigobin CS. The complexities of acute stroke decision-making: a survey of neurologists. *Neurology* 2013;**81**:1130–3. http://dx.doi.org/10.1212/WNL.0b013e3182a55ec7

153. Gillespie R, Mullan J, Harrison L. Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature. *J Clin Nurs* 2014;**23**:3296–308. http://dx.doi.org/10.1111/jocn.12519

154. Busl KM, Nogueira RG, Yoo AJ, Hirsch JA, Schwamm LH, Rost NS. Prestroke dementia is associated with poor outcomes after reperfusion therapy among elderly stroke patients. *J Stroke Cerebrovasc Dis* 2013;**22**:718–24. http://dx.doi.org/10.1016/j.jstrokecerebrovasdis.2011.11.005

155. Sloan FA, Trogdon JG, Curtis LH, Schulman KA. The effect of dementia on outcomes and process of care for Medicare beneficiaries admitted with acute myocardial infarction. *J Am Geriatr Soc* 2004;**52**:173–81. http://dx.doi.org/10.1111/j.1532-5415.2004.52052.x

156. Lawrence V, Murray J, Samsi K, Banerjee S. Attitudes and support needs of black Caribbean, south Asian and white British carers of people with dementia in the UK. *Br J Psychiatry* 2008;**193**:240–6. http://dx.doi.org/10.1192/bjp.bp.107.045187

157. Lawrence V, Samsi K, Banerjee S, Morgan C, Murray J. Threat to valued elements of life: the experience of dementia across three ethnic groups. *Gerontologist* 2011;**51**:39–50. http://dx.doi.org/10.1093/geront/gnq073

158. Bartlett D, McKeefry R. *People with Dementia and Sight Loss: A Scoping Study of Models of Care*. London: Thomas Pocklington Trust; 2009.

159. Lawrence F, Murray J, Banerjee S. *The Experiences and Needs of People with Dementia and Serious Visual Impairment: A Qualitative Study*. London: Thomas Pocklington Trust; 2008.

160. Lawrence V, Murray J. Balancing independence and safety: the challenge of supporting older people with dementia and sight loss. *Age Ageing* 2010;**39**:476–80. http://dx.doi.org/10.1093/ageing/afq054

161. Connolly A, Campbell S, Gaehl E, Iliffe S, Drake R, Morris J, *et al.* Under-provision of medical care for vascular diseases for people with dementia in primary care: a cross-sectional review. *Br J Gen Pract* 2013;**63**:e88–96. http://dx.doi.org/10.3399/bjgp13X663046

162. Allan K. Deafness and dementia: consulting on the issues. *J Dement Care* 2006;**14**:35–7.

163. Alshekhlee A, Mohammadi A, Mehta S, Edgell RC, Vora N, Feen E, *et al.* Is thrombolysis safe in the elderly? Analysis of a national database. *Stroke* 2010;**41**:2259–64. http://dx.doi.org/10.1161/STROKEAHA.110.588632

164. Matthews FE, Arthur A, Barnes LE, Bond J, Jagger C, Robinson L, *et al.* A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet* 2013;**382**:1405–12. http://dx.doi.org/10.1016/S0140-6736(13)61570-6

165. Porter M, Lee T. *The Strategy That Will Fix Health Care. Harvard Business Review*. 2013. URL: https://hbr.org/2013/10/the-strategy-that-will-fix-health-care/ (accessed 9 December 2015).

166. NHS England. *Five Year Forward View*. 2014. URL: www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf (accessed 28 May 2015).

167. Goodwin N, Smith J, Davies A, Perry C, Rosen R, Dixon A, *et al. Integrated Care For Patients and Populations: Improving Outcomes by Working Together*. London: The King's Fund; 2011. URL: www.kingsfund.org.uk/publications/integrated-care-patients-and-populations-improving-outcomes-working-together (accessed 25 November 2014).

168. Dowrick A, Southern A. *Dementia 2014: Opportunity for Change*. London: Alzheimer's Society; 2014. URL: www.alzheimers.org.uk/dementia2014 (accessed 21 March 2015).

169. Field S. *NHS Future Forum: Summary Report on Proposed Changes to the NH*; 2011. URL: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_127540.pdf (accessed 22 April 2015).

170. Shaw S, Rosen R, Rumbold B. *An Overview of Integrated Care in the NHS. What is Integrated Care?* London: Nuffield Trust; 2011.

171. Dementia Partnerships. *Vanguard Sites Selected to Deliver New Models of Care*. 10 March 2015. URL: http://dementiapartnerships.com/vanguard-sites-selected-to-deliver-new-models-of-care/ (accessed 9 December 2015).

172. Béland F, Hollander MJ. Integrated models of care delivery for the frail elderly: international perspectives. *Gac Sanit* 2011;**25**(Suppl. 2):138–46. http://dx.doi.org/10.1016/j.gaceta.2011.09.003

173. Mason A, Goddard M, Weatherly H, Chalkley M. Integrating funds for health and social care: an evidence review. *J Health Serv Res Policy* 2015;**20**:177–88. http://dx.doi.org/10.1177/1355819614566832

174. Smith SM, Soubhi H, Fortin M, Hudon C, O'Dowd T. Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. *BMJ* 2012;**345**:e5205. http://dx.doi.org/10.1136/bmj.e5205

175. Han RC, Jefferis JM, Taylor JP, Archibald NK, Clarke MP. A novel, multidisciplinary clinic for complex visual problems in older people. *Eye* 2012;**26**:1536–41. http://dx.doi.org/10.1038/eye.2012.205

176. Beswick AD, Rees K, Dieppe P, Ayis S, Gooberman-Hill R, Horwood J, *et al.* Complex interventions to improve physical function and maintain independent living in elderly people: a systematic review and meta-analysis. *Lancet* 2008;**371**:725–35. http://dx.doi.org/10.1016/S0140-6736(08)60342-6

177. Stuck AE, Siu AL, Wieland GD, Rubenstein LZ, Adams J. Comprehensive geriatric assessment: a meta-analysis of controlled trials. *Lancet* 1993;**342**:1032–6. http://dx.doi.org/10.1016/0140-6736(93)92884-V

178. Ellis G, Whitehead MA, O'Neill D, Langhorne P, Robinson D. Comprehensive geriatric assessment for older adults admitted to hospital. *Cochrane Database Syst Rev* 2011;**7**:CD006211. http://dx.doi.org/10.1002/14651858.cd006211.pub2

179. Edmans J, Bradshaw L, Franklin M, Gladman J, Conroy S. Specialist geriatric medical assessment for patients discharged from hospital acute assessment units: randomised controlled trial. *BMJ* 2013;**347**:f5874. http://dx.doi.org/10.1136/bmj.f5874

180. Clark M, Moreland N, Greaves I, Greaves N, Jolley D. Putting personalisation and integration into practice in primary care. *J Integr Care* 2013;**21**:105–20. http://dx.doi.org/10.1108/14769011311316033

181. Oliver D, Foot C, Humphries R. *Making our Health and Care Systems Fit for an Ageing Population*. London; The King's Fund: 2014.

182. NHS Hertfordshire. *My Purple Folder. Improving Health Care for People with a Learning Disability Living in Hertfordshire*. Welwyn Garden City: NHS Hertfordshire; 2015. URL: www.hertsdirect.org/docs/pdf/p/purpleeasyfact.pdf (accessed 14 April 2015).

183. Khanassov V, Vedel I, Pluye P. Case management for dementia in primary health care: a systematic mixed studies review based on the diffusion of innovation model. *Clin Interv Aging* 2014;**9**:915–28. http://dx.doi.org/10.2147/CIA.S64723

184. Khanassov V, Vedel I, Pluye P. Barriers to implementation of case management for patients with dementia: a systematic mixed studies review. *Ann Fam Med* 2014;**12**:456–65. http://dx.doi.org/10.1370/afm.1677

185. Koch T, Iliffe S, Manthorpe J, Stephens B, Fox C, Robinson L, *et al.* The potential of case management for people with dementia: a commentary. *Int J Geriatr Psychiatry* 2012;**27**:1305–14. http://dx.doi.org/10.1002/gps.3783

186. Pimouguet C, Lavaud T, Dartigues JF, Helmer C. Dementia case management effectiveness on health care costs and resource utilization: a systematic review of randomized controlled trials. *J Nutr Health Aging* 2010;**14**:669–76. http://dx.doi.org/10.1007/s12603-010-0314-4

187. Reilly S, Miranda-Castillo C, Malouf R, Hoe J, Toot S, Challis D, *et al.* Case management approaches to home support for people with dementia. *Cochrane Database Syst Rev* 2015;**1**:CD008345. http://dx.doi.org/10.1002/14651858.cd008345.pub2

188. Somme D, Trouve H, Drame M, Gagnon D, Couturier Y, Saint-Jean O. Analysis of case management programs for patients with dementia: a systematic review. *Alzheimer's Dement* 2012;**8**:426–36. http://dx.doi.org/10.1016/j.jalz.2011.06.004

189. Tam-Tham H, Cepoiu-Martin M, Ronksley PE, Maxwell CJ, Hemmelgarn BR. Dementia case management and risk of long-term care placement: a systematic review and meta-analysis. *Int J Geriatr Psychiatry* 2013;**28**:889–902. http://dx.doi.org/10.1002/gps.3906

190. Iliffe S, Waugh A, Poole M, Bamford C, Brittain K, Chew-Graham C, *et al.* The effectiveness of collaborative care for people with memory problems in primary care: results of the CAREDEM case management modelling and feasibility study. *Health Technol Assess* 2014;**18**(52). http://dx.doi.org/10.3310/hta18520

191. Van Mierlo L, Meiland F, Van Hout H, Droes R-M. Towards personalized integrated dementia care: a qualitative study into the implementation of different models of case management. *BMC Geriatr* 2014;**14**:84. http://dx.doi.org/10.1186/1471-2318-14-84

192. Minkman MMN, Ligthart SA, Huijsman R. Integrated dementia care in the Netherlands: a multiple case study of case management programmes. *Health Soc Care Community* 2009;**17**:485–94. http://dx.doi.org/10.1111/j.1365-2524.2009.00850.x

193. Goodwin N, Sonola L, Thiel V, Kodner DL. *Co-ordinated Care for People with Complex Chronic Conditions*. London: Aetna Foundation; 2013. URL: www.kingsfund.org.uk/publications/co-ordinated-care-people-complex-chronic-conditions (accessed 7 April 2015).

194. Goodman C, Drennan V, Davies S, Masey H, Gage H, Scott C, *et al. Nurses as Case Managers in Primary Care: the Contribution to Chronic Disease Management*. Southampton: National Institute for Health Research Service Delivery and Organisation programme; 2012. URL: http://eprints.kingston.ac.uk/12331/1/Goodman_Drennan_et_al_122-final-report.pdf (accessed 28 May 2015).

195. Sonola L, Thiel V, Goodwin N, Kodner DL. *Oxleas Advanced Dementia Service Supporting Carers and Building Resilience*. London: The King's Fund; 2013.

196. Griffiths P, Bridges J, Sheldon H, Thompson R. The role of the dementia specialist nurse in acute care: a scoping review. *J Clin Nurs* 2015;**24**:1394–405. http://dx.doi.org/10.1111/jocn.12717

197. Brown M, MacArthur J, McKechanie A, Mack S, Hayes M, Fletcher J. Learning disability liaison nursing services in south-east Scotland: a mixed-methods impact and outcome study. *J Intellect Disabil Res* 2012;**56**:1161–74. http://dx.doi.org/10.1111/j.1365-2788.2011.01511.x

198. MacArthur J, Brown M, McKechanie A, Mack S, Hayes M, Fletcher J. Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'getting it right' for people with learning disabilities receiving general hospitals care. *J Adv Nurs* 2015;**71**:1552–63. http://dx.doi.org/10.1111/jan.12629

199. Phillips L. Improving care for people with learning disabilities in hospital. *Nurs Stand* 2012;**26**:42–8. http://dx.doi.org/10.7748/ns2012.02.26.23.42.c8933

200. La Fontaine J, Brooker D, Bray J, Milosevic S. *A Local Evaluation of Dementia Advisers (National Demonstrator Site). Worcestershire Report for Dementia Adviser Service Implementation Team*. Worcester: Association for Dementia Studies, University of Worcester; 2011.

201. Clarke CL, Keyes SE, Wilinson H, Alexjuk J, Wilcockson J, Robinson L, *et al. HEALTHBRIDGE. The National Evaluation of Peer Support Networks and Dementia Advisers in Implementation of the National Dementia Strategy for England*. Department of Health Policy Research Programme Project. London: Department of Health; 2013.

202. Robertson J, Roberts H, Emerson E. *Health Checks for People with Learning Disability: a Systematic Review of Evidence*. 2010. URL: www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010–04HealthChecksSystemticReview.pdf (accessed 14 April 2015).

203. National Institute for Health and Care Excellence. London: NICE; 2014. *NICE Pathways: Diabetes Overview*. URL: http://pathways.nice.org.uk/pathways/diabetes (accessed 28 May 2015).

204. Mayrhofer A, Goodman C, Sharpe R, Dye H. *Dementia Education in Hertfordshire and Bedfordshire: an Organisational Audit Commissioned by Health Education East of England*. Hatfield: Centre for Research in Primary and Community Care (CRIPACC), University of Hertfordshire; 2014.

205. Livingston G, Leavey G, Manela M, Livingston D, Rait G, Sampson E, *et al.* Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ* 2011;**341**:c4184. http://dx.doi.org/10.1136/bmj.c4184

206. Knapp M, Black N, Dixon J, Damant J, Rehill A, Tan S. *Independent Assessment of Improvements in Dementia Care and Support Since 2009*. Report from the Policy Innovation and Research Unit and the NIHR School for Social Care Research. London: PIRU; 2014.

207. Gordon AL, Franklin M, Bradshaw L, Logan P, Elliott R, Gladman JR. Health status of UK care home residents: a cohort study. *Age Ageing* 2014;**43**:97–103. http://dx.doi.org/10.1093/ageing/aft077

208. Boyer F, Novella JL, Morrone I, Jolly D, Blanchard F. Agreement between dementia patient report and proxy reports using the Nottingham Health Profile. *Int J Geriatr Psychiatry* 2004;**19**:1026–34. http://dx.doi.org/10.1002/gps.1191

209. Freeman G, Hughes J. *Continuity of Care and the Patient Experience*. London: The King's Fund; 2010. URL: www.kingsfund.org.uk/sites/files/kf/field/field_document/continuity-care-patient-experience-gp-inquiry-research-paper-mar11.pdf (accessed 16 April 2015).

210. Aboulghate A, Abel G, Elliott MN, Parker RA, Campbell J, Lyratzopoulos G, *et al.* Do English patients want continuity of care, and do they receive it? *Br J Gen Pract* 2012;**62**:e567–75. http://dx.doi.org/10.3399/bjgp12X653624

211. Freeman GK. Progress with relationship continuity 2012, a British perspective. *Int J Integr Care* 2012;**12**:e128.

212. McCarthy M, Addington-Hall J, Altmann D. The experience of dying with dementia: a retrospective study. *Int J Geriatr Psychiatry* 1997;**12**:404–9. http://dx.doi.org/10.1002/(SICI)1099-1166(199703)12:3<404::AID-GPS529>3.0.CO;2-2

213. Miranda-Castillo C, Woods B, Orrell M. People with dementia living alone: what are their needs and what kind of support are they receiving? *Int Psychogeriatr* 2010;**22**:607–17. http://dx.doi.org/10.1017/S1041610210000013X

214. Redley M, Banks C, Foody K, Holland A. Healthcare for men and women with learning disabilities: understanding inequalities in access. *Disabil Soc* 2012;**27**:747–59. http://dx.doi.org/10.1080/09687599.2012.673080

215. Piette JD, Kerr EA. The impact of comorbid chronic conditions on diabetes care. *Diabetes Care* 2006;**29**:725–31. http://dx.doi.org/10.2337/diacare.29.03.06.dc05-2078

216. Kerr EA, Heisler M, Krein SL, Kabeto M, Langa KM, Weir D, *et al.* Beyond comorbidity counts: how do comorbidity type and severity influence diabetes patients' treatment priorities and self-management? *J Gen Intern Med* 2007;**22**:1635–40. http://dx.doi.org/10.1007/s11606-007-0313-2

217. Jefferis JM, Taylor JP, Clarke MP. Does cognitive impairment influence outcomes from cataract surgery? Results from a 1-year follow-up cohort study. *Br J Opthalmol* 2015;**99**:412–17. http://dx.doi.org/10.1136/bjophthalmol-2014-305657

218. Creasy KR, Lutz BJ, Young ME, Stacciarini J-MR. Clinical implications of family-centered care in stroke rehabilitation [published online ahead of print 3 February 2015]. *Rehabil Nurs* 2015. http://dx.doi.org/10.1002/rnj.188

219. Department of Health. *Dementia Friendly Environments Funding: Successful Bids*. London: Department of Health; 2013. URL: www.gov.uk/government/publications/dementia-friendly-environments-funding-successful-bids (accessed 28 May 2015).

220. The Butterfly Scheme. URL: http://butterflyscheme.org.uk/ (accessed 5 January 2016).

221. The Health Foundation. *Spotlight on Dementia Care. A Health Foundation Improvement Report*. London: The Health Foundation; 2011. URL: www.health.org.uk/publication/spotlight-dementia-care (accessed 5 January 2016).

222. Norfolk Age UK. *Pabulum Blue Book*. URL: www.ageuk.org.uk/norfolk/dementia-support–services/pabulum-blue-book/ (accessed 5 January 2016).

223. The Charity for Civil Servants. *Carer's Passport*. URL: www.foryoubyyou.org.uk/helping-you/caring/carers-passport (accessed 5 January 2016).

224. Bray J, Evans S, Thompson R, Bruce M, Carter C, Brooker D, *et al.* Understanding the needs of people with dementia and family carers. *Nurs Older People* 2015;**27**:18–23. http://dx.doi.org/10.7748/nop.27.7.18.e699

225. Kitwood T. Towards a theory of dementia care: the interpersonal process. *Ageing Soc* 2008;**13**:51–67. http://dx.doi.org/10.1017/S0144686X00000647

226. National Institute for Health and Care Excellence. *Guidelines on Supporting People with Dementia and their Carers*. London: British Psychological Society and the Royal College of Psychiatrists; 2007.

227. Clissett P, Porock D, Harwood RH, Gladman JR. The challenges of achieving person-centred care in acute hospitals: a qualitative study of people with dementia and their families. *Int J Nurs Stud* 2013;**50**:1495–503. http://dx.doi.org/10.1016/j.ijnurstu.2013.03.001

228. Alzheimer's Society. *This is Me – Tool for People with Dementia Receiving Professional Care*. London: Alzheimer's Society; 2015. URL: http://alzheimers.org.uk/thisisme (accessed 23 April 2015).

229. Alzheimer's Disease International. *World Alzheimer Report 2011. The Benefits of Early Diagnosis and Intervention*. London: Alzheimer's Disease International; 2011. URL: www.alz.co.uk/research/world-report-2011 (accessed 26 May 2015).

230. Callahan CM, Boustani MA, Unverzagt FW, Austrom MG, Damush TM, Perkins AJ, *et al.* Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA* 2006;**295**:2148–57. http://dx.doi.org/10.1001/jama.295.18.2148

231. Bamford C, Poole M, Brittain K, Chew-Graham C, Fox C, Iliffe S, *et al.* Understanding the challenges to implementing case management for people with dementia in primary care in England: a qualitative study using normalization process theory. *BMC Health Serv Res* 2014;**14**:549. http://dx.doi.org/10.1186/s12913-014-0549-6

232. National Audit Office. *Improving Services and Support for People with Dementia*. London: HMSO; 2007. URL: www.nao.org.uk/wp-content/uploads/2007/07/0607604.pdf (accessed 28 May 2015).

233. Tullo E, Allan L. What should we be teaching medical students about dementia? *Int Psychogeriatr* 2011;**23**:1044–50. http://dx.doi.org/10.1017/S1041610211000536

234. Royal College of General Practitioners. *The 2022 GP. A Vision for General Practice in the Future NHS*. London: Royal College of General Practitioners; 2013. URL: www.rcgp.org.uk/policy/rcgp-policy-areas/general-practice-2022.aspx (accessed 4 January 2016).

235. Department of Health. *Prime Minister's Challenge on Dementia: Delivering Major Improvements in Dementia Care and Research by 2015*. London: Department of Health; 2012.

236. Department of Health. *Delivering High Quality, Effective, Compassionate Care: Developing the Right People with the Right Skills and the Right Values. A Mandate from the Government to Health Education England: April 2014 to March 2015*. May 2014. URL: www.gov.uk/government/uploads/system/uploads/attachment_data/file/310170/DH_HEE_Mandate.pdf (accessed 4 January 2016).

237. Department of Health. *Nothing Ventured, Nothing Gained: Risk Guidance for Dementia*. London: Department of Health; 2010. URL: www.gov.uk/government/uploads/system/…/dh_121493.pdf (accessed 27 May 2015).

238. Bloomfield HE, Greer N, Newman D, MacDonald R, Carlyle M, Fitzgerald P, *et al. Predictors and Consequences of Severe Hypoglycemia in Adults with Diabetes – a Systematic Review of the Evidence*. Washington, DC: Institute for Family-Centered Care; 2012. URL: www.ncbi.nlm.nih.gov/pubmedhealth/PMH0050531/pdf/PubMedHealth_PMH0050531.pdf (accessed 27 May 2015).

239. Weber SR, Pirraglia PA, Kunik ME. Use of services by community-dwelling patients with dementia: a systematic review. *Am J Alzheimers Dis Other Demen* 2011;**26**:195–204. http://dx.doi.org/10.1177/1533317510392564

240. Peel E, Harding R. 'It's a huge maze, the system, it's a terrible maze': dementia carers' constructions of navigating health and social care services. *Dementia (London)* 2014;**13**:642–61. http://dx.doi.org/10.1177/1471301213480514

241. Ibrahim JE, Davis M-C. Availability of education and training for medical specialists about the impact of dementia on comorbid disease management. *Educ Gerontol* 2013;**39**:925–41. http://dx.doi.org/10.1080/03601277.2013.767657

242. Ory MG, Hoffman RR III, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist* 1999;**39**:177–85. http://dx.doi.org/10.1093/geront/39.2.177

243. Frampton S, Guastello S, Brady C, Hale M, Horowitz S, Bennett Smith S, *et al. Patient-Centered Care: Improvement Guide*. Derby, CT: Planetree/Picker Institute; 2008. URL: http://planetree.org/wp-content/uploads/2012/01/Patient-Centered-Care-Improvement-Guide-10-28-09-Final.pdf (accessed 22 April 2015).

244. Jurgens FJ, Clissett P, Gladman JR, Harwood RH. Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study. *BMC Geriatr* 2012;**12**:57. http://dx.doi.org/10.1186/1471-2318-12-57

245. Johnson B, Abraham M, Conway J, Simmons L, Edgman-Levitan S, Sodomka P, *et al. Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System*. Bethesda, MD: Institute for Patient- and Family-Centered Care and Institute for Healthcare Improvement; 2008. URL: www.ihi.org/resources/Pages/Publications/PartneringwithPatientsandFamilies.aspx (accessed 22 April 2015).

246. Future Hospital Commission. *Future Hospital: Caring for Medical Patients*. A report from the Future Hospital Commission to the Royal College of Physicians, September 2013. URL: www.rcplondon.ac.uk/projects/future-hospital-commission (accessed 8 April 2015).

247. Clarke CL. Risk: constructing care and care environments in dementia. *Health Risk Soc* 2000;**2**:83–93. http://dx.doi.org/10.1080/136985700111477

248. Manthorpe J. *Risk Taking*. London: Jessica Kingsley; 2004.

249. Rubenstein RS, Lohr ICN, Brook RH, Goldberg GA. *Conceptualisation and Measurement of Physiological Health for Adults: Volume 12 Vision Impairments*. Bethesda, MD: US Department of Health and Human Sciences/Rand Corporation; 1982.

250. Spreen O, Strauss E. *A Compendium of Neuropsychological Tests: Administration, Norms and Commentary*, 2nd edn. New York, NY: Oxford University Press; 1998.

Appendix 1 Details of search terms

Search terms for the scoping review: PubMed

Search component	Search terms
#1 Dementia and diabetes	((Dementia OR Alzheimer OR cognitive impairment OR delirium) AND (Diabetes OR blood glucose self-monitoring) (Self management OR Self Care OR Self monitoring OR Service delivery OR Service organization OR Activities of daily living OR Caregivers OR Quality Assessment OR Quality OR Quality Indicators OR Quality of life OR Disease Progression OR Behaviour OR Impact OR Geriatric Assessment OR Severity of Illness OR Nursing Assessment OR Interprofessional OR Standard of Care OR Risk Factors OR Treatment outcome OR patient Experience) AND (Humans[Mesh]))
#2 Dementia and stroke	(Dementia[ti] OR Alzheimer[ti]) AND (stroke OR cerebrovascular OR CVA OR cerebrovascular disorders) AND (Self management OR Self Care OR Self monitoring OR Service delivery OR Service organization OR Activities of daily living OR Caregivers OR Quality Assessment OR Quality OR Quality Indicators OR Quality of life OR Disease Progression OR Behaviour OR Impact OR Geriatric Assessment OR Severity of Illness OR Nursing Assessment OR Interprofessional OR Standard of Care OR Risk Factors OR Treatment outcome OR patient Experience) AND (Humans[Mesh]))
#3 Dementia and visual impairment	(Dementia OR Alzheimer OR cognitive impairment OR delirium) AND (Eye diseases OR vision disorders OR Blindness OR visually impaired OR Nystagmus OR retinopathy OR macular degeneration OR glaucoma or cataract) AND (Self management OR Self Care OR Self monitoring OR Service delivery OR Service organization OR Activities of daily living OR Caregivers OR Quality Assessment OR Quality OR Quality Indicators OR Quality of life OR Disease Progression OR Behaviour OR Impact OR Geriatric Assessment OR Severity of Illness OR Nursing Assessment OR Interprofessional OR Standard of Care OR Risk Factors OR Treatment outcome OR patient Experience)
#4 Dementia and comorbidity	((Dement*[ti] OR Alzheimer*[ti]) AND ((comorbidity OR co-morbidity OR comorbid OR "other medical conditions" OR "other chronic disease*" OR multimorbidiy[ti] OR multi-morbidity[ti] OR multiple disease*[ti] OR multiple morbid*[ti] OR polypathology[ti] OR associated disease*[ti] OR associated disorder*[ti]) OR co-existence[ti] OR co-existing[ti] OR concomitant[ti] OR co-occurring[ti]))
#5	#1 OR #2 OR #3 OR #4 OR #5

Search strategy to support ideas/recommendations from the consensus conference

The following search terms were used in PubMed (searched March 2015):

((continuity[Title] OR access[Title] OR integration[Title] OR integrated[Title] OR management[Title] OR navigate*[Title]) AND ((dementia[Title] OR alzheimer*[Title] OR MCI[Title] OR cognitive[Title] OR multimorbid*[Title] OR comorbid*[Title] OR frail*[Title] OR complex[Title]) AND (Review[ptyp]))

The following terms were used in The Cochrane Library (searched March 2015):

(continuity OR access OR integration OR integrated OR management OR navigate*) AND (dementia OR alzheimer* OR MCI OR cognitive OR multimorbid* OR comorbid* OR frail* OR complex)

The following terms were used in Google Scholar (searched March 2015):

Case management AND dementia

Integration OR integrated AND dementia

Continuity AND dementia

Care pathway AND dementia

Patient held records AND dementia

Shared records AND dementia

Electronic records AND dementia

Comprehensive geriatric assessment AND dementia

Learning disability AND health care

Learning disability AND continuity

Appendix 2 Interview and focus group schedules

Interview schedule for people living with dementia: process summary and core questions

1. Introduction/warm-up and gaining consent

- Researcher will introduce themselves and explain that they are from the University of Hertfordshire/ Newcastle University.
- Thank participant for taking part in the research and explain that this is a study looking at how memory problems affect how people manage other health conditions, for example diabetes, stroke or sight loss.
- Provide details on how the research team can be contacted after the interview.
- Give details about the format of the interview (semistructured) and time.
- Travel expenses forms are available from us should you require one (if applicable).
- We will give you your £10 voucher at the end of the interview.
- Are there any questions?

Consent – Assess person with dementia's capacity to participate in the interview and record this.

- *Please look at this information and then tell me how you feel*. Ask that participant (person with dementia and/or carer) reads and signs the consent form (consent can range from signing the consent form to recording verbal consent).
- Explanation of anonymity and confidentiality and that the interview will be recorded.
- You may stop the interview at any point, you don't have to share personal experiences if you don't want to.
- You don't have to answer any questions you don't want to.
- Note ways in which decreasing level of well-being can be recognised.

2. Participant background/bio (conversational to find out about the person)

Probe for:

- Have they always lived in current area or are they from another area.
- Previous employment.
- Education level.
- Family – married/widowed, children/grandchildren.
- What carers there are? Who else lives with them?
- Ask about family support – how often do they see/speak to family and friends?
- Any help from social services/day centres/carers coming to house/community nurses?

3. Health problems and comorbidities

- I'd like to know about your health problems.
- Ask about the medication they are taking.
- Do you take any tablets specifically for your memory problems?

Prompt:

Find out when difficulty with memory began – before or after comorbidity? Could affect how they self-manage. Diabetes, sight loss and stroke – how long have they had these conditions (avoid spending too much time on other health conditions).

Diabetes	Stroke	VI
• Difficulties administering medication (oral or injections) • Forgetting to take medication • Altering medications • Low blood sugar/testing sugar levels • Diet • Dependency on carers • Whether diabetes is neglected • Lack of knowledge and understanding of diabetes	• Whether memory problems impact on stroke recovery • Treatment at time of stroke, e.g. scans, blood clots • Taking medication for prevention of future strokes (tablets for blood pressure, a cholesterol-lowering tablet and a blood-thinning tablet, not just aspirin) • Rehabilitation exercises • Dependency on carers • Whether stroke is neglected • Lack of knowledge and understanding about their stroke condition, treatment or rehabilitation • Problems with memory and speech – difficulties with communication • Alcohol/smoking	• Whether memory problems impact on self-management • Eye drops/ointment • Dependency on carers • Whether sight loss issues are neglected because of dementia • Lack of knowledge and understanding about sight loss condition, medications/treatment • Whether dementia prevents eligibility for surgery/other treatments

4. Management of condition

- Do your memory problems affect how you manage your diabetes/sight problems/stroke recovery?
- (Note any problems with self-management or any effective strategies to self-manage condition.)
- Does having sight a problem make it more difficult to remember things? (VI only) Probe for whether comorbidity causes memory to be worse, e.g. a person with a sight problem may forget to take medication because of a lack of visual cues/not having information in large print.

5. Health-care experiences

I'd like to know a bit more about the health care/treatment that you have received for your diabetes/sight problems/stroke:

- Do you see a regular team about your diabetes/sight problems/stroke? (*Prompt*: do they see the same professional, is there continuity of care?)
- Who is the health professional you see most often about your diabetes/sight problems/stroke? (*Prompt*: GP/practice nurse/nurse specialist/consultant in hospital practice and community. Explore whether the HCP has dementia expertise as well as comorbidity expertise)
- Does he/she spend enough time with you? Explain things to you? (About condition, how to take medication, health-care services available.) Do they seem to know about you and your problems?
- What sort of information have you been given about your diabetes/sight problems/stroke? (*Prompt*: leaflets/information sheets/verbal explanation) (pursue the information they receive, any training courses, e.g. diabetes management). Prompt for 'This is me'.
- Do you have regular check-ups for your diabetes/sight problems/stroke? [*Prompt*: interested in whether they are neglected for regular check-ups, e.g. regular visits to diabetes clinic, eye examinations, annual blood tests for diabetes with follow-up appointments and annual eye screening (as required by guidelines)]. Do they get reminders?
- Have you missed any appointments and what happened? (Have they been taken off waiting lists?)
- Do you see a regular team about your memory problems? Do you think that the different health teams share information with each other? (*Prompt*: about how their care is managed/co-ordinated across different specialist teams, e.g. diabetes teams sharing information with dementia specialists; anything like 'This is me' being used?)
- Have you joined any voluntary organisations like Diabetes UK, RNIB, Stroke Association, etc.? Do they get specialist advice from these organisations?

Diabetes	Stroke	VI
• Diabetes clinic/hospital experiences • Someone to check their mood • Day centre	• Treatment at time of the stroke/ rehabilitation/physiotherapy/occupational therapy/speech therapy • Someone to check their mood • Day care/respite care	• Visit to eye specialist/ophthalmic doctor/cataract surgeon • Someone to check their mood • Day centre/voluntary worker

I'd like to know what it is like when you visit the hospital or a clinic about your diabetes/sight problems/stroke:

- What was your experience like? (*Prompts*: find out which health-care services they have access to)
- Did the doctors and nurses understand about your memory problems? (*Prompt*: did they know about the person's dementia/provide extra help)
- Does he/she/they spend enough time with you? Explain things to you?

6. What is working well and what could be improved? (re-orient back to examples given by participant)

- What has been good about the care you have received?
- What do you think has *not* been good about the care you have received?
- Is there any treatment that you would like to have that isn't available to you?
- Are there any health-care services that you think would be helpful to you?
- Would you like any support to help with your diabetes/stroke/sight problems?

Help the person with dementia to make the transition from the research context back into their day-to-day context.

I can explain anything if you need me to. Many thanks for your time and support of this study.

Focus group schedule

Introduction

- Welcome and thanks for attending.
- Who we are – the researchers in attendance introduce themselves (AB can be contacted following the focus group).
- Summary of what we are trying to achieve – want to begin by looking generally at the extent to which you feel that dementia is an issue, move onto some issues relating more specifically to stroke care and pathways and what you think a good service would look like and then finish with looking at general initiatives relating to the improvement of hospital care for people with dementia.

Consent

- Ask that everyone reads and signs the consent form.
- Consent form for each individual.
- Explanation of anonymity and confidentiality.
- The focus groups will be recorded.
- You may leave at any point, you don't have to share personal experiences if you don't want to.

Other instructions

- Once you are sitting down with your group you may like to begin by introducing yourselves to the other people in your group.
- When we begin the focus groups, everyone should have a say, please don't interrupt each other.

Questions for stroke health-care professionals (schedule was adapted for each specialism)

1. In your experience to what extent is dementia an issue when providing care for stroke patients?
    i. How does dementia impact on the service you provide?
    ii. Is the problem increasing?

2. How does it impact on the stroke care pathway if someone has dementia?
    i. Does it affect decisions about brain scanning?
    ii. Does it affect decisions about thrombolysis or other treatment?
    iii. Where would people go – e.g. hyperacute unit, rehabilitation unit, geriatric ward or specialist dementia unit?
    iv. Who would be responsible for the care of people with dementia who have had a stroke?
    v. How would it impact on decisions about rehabilitation?

3. In an ideal world what do you think a good stroke service for people with dementia would look like?
    i. Would it be the same as the current NICE [National Institute for Health and Care Excellence] pathway or would it differ in any way?
    ii. How would you see family carers being involved?

4. How does the presence of dementia impact on secondary stroke prevention?
    i. Compliance with medication, diet, etc.

5. Are there any initiatives that you are aware of in the hospital to improve the care of people with dementia?
    i. Dementia champions?
    ii. Wrist bands?
    iii. 'This is me'?
    iv. Special facilities for patients with dementia?

6. What are the knowledge gaps among providers of stroke services about dementia?
    i. Are there areas where you feel that you need more information/education?

7. Is there anything else you would like to add? Anything we haven't covered?

Thank participants for their time.

Appendix 3 Template for nominal group technique at the consensus conference

	My idea is called …
Name the idea	
	My idea is …
Explain the idea	
	My idea would be good because …
Summarise the benefits	
	The main obstacles to overcome before the idea could be delivered would be …
Summarise the barriers	

Appendix 4 Additional tables for the scoping review

TABLE 12 Details of studies included in the scoping review

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Allan *et al.*, 2005[89] (Allan 2006[162])	UK	Qualitative	Total: 43 ($n = 12$ service users with hearing impairment, $n = 16$ practitioners, $n = 8$ relatives, $n = 7$ British Sign Language interpreters)	Consultation exercise looking at issues for people with dementia with hearing loss	V	Hearing impairment	NR	NR
Australian Commission on Safety and Quality in Health Care 2013[88]	Australia	Rapid review	NA	To identify best practice in caring for patients with cognitive impairment in acute hospital settings	S	General	NA	NA
Alshekhlee *et al.*, 2011[151]	USA	Cohort study	35,557 patients with a diagnosis of dementia; 207 (0.58%) had received thrombolysis	To establish the impact of dementia on hospital mortality and intracerebral haemorrhage rates associated with thrombolysis therapy for AIS	A	Stroke	Most aged > 80	63
Balfour and O'Rourke 2003[90]	Canada	Cross-sectional	Total: 460 PLWD ($n = 245$ with arthritis, $n = 215$ no arthritis)	Are patients with Alzheimer's disease inappropriately prescribed neuroleptics and benzodiazepines	Q	Arthritis	84.33	73
Barnett *et al.*, 2012[91] (Guthrie *et al.*, 2012[4])	UK	Cross-sectional	1,751,841 patients from database of primary care practices	Examined distribution of multimorbidity and comorbidity in relation to age and socioeconomic deprivation	P	General multimorbidity but includes information on diabetes and stroke	16.6% aged ≥ 65	50.5
Bartlett and McKeefry 2011[93] (Bartlett and McKeefry 2009[158])	UK	Qualitative and scoping	7 practitioners, 4 students	To increase knowledge of visual issues and eye health for people with dementia	V	VI	NR	NR
Bartlett and Clarke 2012[92]	UK	Qualitative	5 HCPs	How HCPs assess the needs of and communicate with a person dying from cancer with a coincidental dementia	V	Cancer	NR	100

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Bayer *et al.*, 1994[94]	UK	Prevalence study	26 older people with diabetes (in all but five, diabetes predated dementia)	Impact of dementia on diabetic care	V	Diabetes	Median 78.5 (range 70–91)	73
Beishon *et al.*, 2014[149]	NA	Systematic review	Includes six RCTs	Assess the evidence for the treatment of hypertension in older people with dementia	A	Hypertension	≥ 65	NR
Bruce *et al.*, 2003[95]	Australia	Cross-sectional	223 older people with diabetes	Determine whether or not the prevalence of dementia in older diabetics warrants an active screening approach	P	Dementia and depression in people with diabetes	76.5	48.8
Busl *et al.*, 2013[154]	USA	Retrospective cross-sectional	153 (13.6% pre-stroke dementia)	To determine whether or not pre-stroke dementia contributed to poor outcomes in stroke patients aged > 80 years who underwent intravenous and/or IAT reperfusion	A	Stroke	86	NR
College of Optometrists 2012[96]	UK	Guidelines	NA	Guidelines for optometrists examining a patient with dementia or cognitive impairment	S	VI	NA	NA
Connolly *et al.*, 2013[161] (Connolly *et al.*, 2012[97])	UK	Observational, cross-sectional review of primary care records	700 PLWD (compared with people without dementia on QOF register)	Evaluate the quality of medical care for vascular diseases provided to people with dementia	Q	Stroke and diabetes	82.1 (43–102)	66
Curtis *et al.*, 2012[98]	USA	Retrospective cohort study	284,380 (with and without dementia)	Examine use of treatments for AMD	Q	VI (AMD)	81	64
Dewing and Dijk 2014[99]	UK	Literature review	NA	Review of the literature on the acute care of PLWD in general hospitals	V, S	General	NA	NA

continued

TABLE 12 Details of studies included in the scoping review (*continued*)

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Doraiswamy *et al.*, 2002[1]	USA	Cross-sectional	679 older people with Alzheimer's disease	Examine the prevalence of comorbid medical illness in Alzheimer's disease patients	P	General	87	Community 55.6, assisted living 75.8, nursing home 83.5
Doucet *et al.*, 2008[100]	France	Cross-sectional	238 older people with diabetes	Identify characteristics of elderly diabetic patients and evaluate relationship between glycaemic control and complications of diabetes	Q	Diabetes	82.2	58
Feil *et al.*, 2003[101]	USA	Longitudinal cross-sectional	7482 older adults	Examine relationship between cognitive impairment, common chronic medical illnesses and risk of mortality in older people	P	Several but includes diabetes and stroke	51% aged ≥ 85	61
Feil *et al.*, 2009[103]	USA	Longitudinal cross-sectional	51 people with diabetes ($n = 27$ with caregiver)	Examine role of cognitive impairment and caregiver support in diabetes care adherence and glycaemic control	P, Q	Diabetes	78 (62–90)	0
Feil *et al.*, 2011[102]	USA	Qualitative	21 caregivers of PLWD and diabetes	Explore caregivers' challenges and quality-of-life issues managing diabetes in PLWD	V	Diabetes	65–90	Majority female (numbers not given)
Feil *et al.*, 2011[104]	USA	Cross-sectional database analysis	497,000 veterans with diabetes (with and without cognitive impairment/dementia)	Examine the relationship between management of diabetes and hypoglycaemia in older adults with dementia	P, Q	Diabetes	100% aged > 65, 44% aged > 75	2
Formiga *et al.*, 2009[105]	Spain	Prospective population-based survey	515 PLWD	Evaluate comorbidity in elderly with dementia to determine differences according to dementia severity	P	General	81	70
George *et al.*, 2011[106]	UK	Systematic review		Examine literature to determine the evidence for the effectiveness of joint geriatric/psychiatric wards	S	General	NA	NA

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Gillespie *et al.*, 2014[153]	NA	Systematic review/scoping	10 studies ($n = 5$ USA, $n = 2$ UK, $n = 2$ Australia, $n = 1$ Canada)	To explore published literature that describes what is known about the role of informal caregivers as they manage medications for older adults and/or PLWD resident in the community	V	General	NR	NR
Gladman *et al.*, 2012[107]	UK	Qualitative study (and review)	60 HCPs, 36 patient and carer interviews	Elicit staff and organisational attitudes to dealing with older patients with cognitive impairment, understand the impact on patients, carers and staff and identify potential improvements	V	General	Patients 86.8 (70–99), carers 63 (46–79)	HCPs 80, patients 56
Gold *et al.*, 1996[108]	USA	Case–control	52 patients attending a memory clinic ($n = 30$ dementia, $n = 22$ cognitive impairment)	Determine prevalence and characteristics of hearing loss and whether screening tools are adequate and patients with Alzheimer's disease can adequately report hearing problems	P	Hearing loss	NR	83
Goldberg *et al.*, 2013[109]	UK	RCT	310 intervention group, 290 control group	Develop and evaluate a best practice model of general hospital acute medical care for older people with cognitive impairment	S	General	Median 85	Intervention group 55, control group 40
Guijarro *et al.*, 2010[110]	Spain	Cohort	40,482 PLWD	Determine prevalence and clinical characteristics of hospitalised dementia patients	P, Q	Several including cataracts and diabetes	78	NR
Heun *et al.*, 2013[12]	UK	Retrospective case–control	634 with Alzheimer's disease, 72,244 control group	Differences between Alzheimer's disease and non-Alzheimer's disease patients in terms of comorbid diseases at hospital admission and which comorbidities contribute to mortality	P	General	Alzheimer's disease 85.1 (SE 8.2), control 80.8 (SE 7.4)	Alzheimer's disease 65, control 51

continued

TABLE 12 Details of studies included in the scoping review (*continued*)

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Hewitt *et al.*, 2010[20]	UK	Questionnaire survey	1047 older people with type 2 diabetes	Examine knowledge and management of diabetes in older people	P, V	Diabetes	80.9 (75–100)	53.3
Hill *et al.*, 2013[112]	UK	Guidance	NA	Highlight importance of recognising relationship between diabetes and dementia, the impact one condition has on the other and maximising the benefits and safety of diabetes treatments while minimising risks	Q	Diabetes	NA	NA
Hoffman *et al.*, 2011[111]	Germany	Cohort	1848 PLWD	Determine whether or not comorbidity and polypharmacy influence prescription of cholinesterase inhibitors in PLWD	Q	General comorbidity but some mention of visual disturbances	78.7	47.6
Holmes *et al.*, 2010[113]	UK	Literature review, mapping and case study	10 case study sites: recruited 757 participants in the referred cohort and 975 participants in the comparison cohort	Establish what service models are being used to improve the care of older people with mental health problems in general hospitals and what impact these models might have on outcomes	S	General	80	Comparison cohort 55, referred cohort 64%
Ishii *et al.*, 2008[114]	Japan	Case series	88 people with VI	Evaluate the influence of cataract surgery on cognitive function and depressive mental status of elderly patients	Q	VI	75.3 (55–93)	64
Jara *et al.*, 2011[144]	USA (but UK data)	Retrospective cohort	8124 Alzheimer's disease cohort, 642,325 non-Alzheimer's disease cohort	Evaluate the occurrence of cataracts in people with Alzheimer's disease compared with the general population	P	VI	64+	Alzheimer's disease cohort 68, non-Alzheimer's disease cohort 54

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Jefferis *et al.*, 2011[115]	UK	Literature review	NA	What are the implications for practice relating to the benefits of cataract surgery for PLWD?	Q	VI (cataracts)	NA	NA
Jones and Trigg 2007[116] (Trigg and Jones 2005[73])	UK	Scoping review	NA	Review of research on PLWD and serious sight loss	P, Q	VI	NA	NA
Keenan 2014[117]	UK	Cohort	65,894 AMD cohort, 168,092 dementia cohort	Are PLWD more or less likely to be admitted to hospital for AMD treatment	Q	VI (AMD)	Majority >65	61
Lawrence *et al.*, 2009[72] (Lawrence *et al.*, 2008,[156] 2010,[160] 2011[157])	UK	Qualitative	17 PLWD and VI, 17 family caregivers, 18 HCPs	The experiences and needs of older adults with VI and dementia	V	VI	65–99 (18/19 aged ≥75)	63
Löppönen *et al.*, 2004[118]	Finland	Cross-sectional population-based study	1260 older people, 112 PLWD	Study of undiagnosed diseases in older people with and without dementia	P, Q	Several including diabetes, stroke and VI	64+	58
Lyketsos *et al.*, 2005[119]	USA	Case–control	695 older people; 149 PLWD, 225 without cognitive impairment, 321 cognitive impairment no dementia	Investigated medical comorbidity in persons with dementia and cognitive impairment	P	General	Dementia 83.89, CIND 82.38, no dementia 79.93	Dementia 64.4, CIND 53.8, no dementia 54.8
MacKenzie *et al.*, 2011[120]	Canada	RCT	56 stroke and MCI patients	Investigate whether nurse case management interventions result in lowered blood pressure	S	Mainly stroke but includes diabetes	59% >65	30
McCormick *et al.*, 1994[121]	USA	Case–control	Total: 375 ($n=154$ with dementia, $n=92$ with cognitive impairment, $n=129$ control group)	Compare comorbidity in Alzheimer's disease patients and non-Alzheimer's disease patients	P	General	76	Dementia 68, cognitive impairment 57, control 63
McKeefry and Bartlett 2010[122] (McKeefry and Bartlett 2010[74])	UK	Scoping review	NA	To develop guidelines for optometrists for best practice with patients with dementia and sight loss	S	VI	NA	NA

continued

TABLE 12 Details of studies included in the scoping review (*continued*)

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Müther *et al.*, 2010[123]	Germany	Retrospective matched control study	216 PLWD, 216 matched control subjects without dementia	Are patients with dementia treated differently from patients without dementia?	Q	Several, includes diabetes	dementia group 82.7, non-dementia group 82.2	77.3
Parke *et al.*, 2011[124]	Canada	Scoping review	Included 15 evaluation studies	Scope research on cognitive impairment in older adults who visited the emergency department of an acute care hospital and evaluation of effectiveness of programmes	S	General	65+	NA
Parke *et al.*, 2013[125]	Canada	Qualitative	10 adult–family caregiver dyads, 10 emergency department nurses, 4 nurse practitioners	Identify factors that facilitate or impede safe transitional care in the emergency department for community-dwelling older adults	S, V	General	PLWD 83.17 (77–90), carer 57.81 (51–84)	Not specified
Pendlebury and Rothwell 2009[69]	NA	Systematic review	22 hospital-based and 8 population-based cohorts	Identify the risk factors for dementia and whether or not there are any differences in the risk factors associated with pre-stroke and post-stroke dementia	P	Stroke	NA	NA
Pendlebury *et al.*, 2015[146]	UK	Cross-sectional	1236 patients with acute transient ischemic attack or stroke	To determine the impact of study entry criteria on measured rates of pre- and post-event dementia	P	Stroke	75	53
Poblador-Plou *et al.*, 2014[14]	Spain	Cross-sectional	72,815 [3971 (5.45%) diagnosed with dementia]	To look at the prevalence of chronic conditions in PLWD	P	General	70 whole sample, 80 PLWD	70
Poland *et al.*, 2014[148]	UK	Qualitative	9 carers of PLWD	To identify carers' views gained from experiences of medication management in dementia	V	General	NR	89
Rabadi *et al.*, 2008[126]	USA	Retrospective analysis	668 ($n = 435$ with cognitive impairment)	Can stroke patients with cognitive impairment benefit from admission to an acute rehabilitation unit?	S	Stroke	70.3 (22–96)	53

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Rait *et al.*, 2010[127]	UK	Cohort	22,529 PLWD, 112,645 matched non-dementia participants. Ratio of 1 : 5 dementia : non-dementia	Estimate survival after diagnosis of dementia in primary care compared with people without dementia and determine incidence of dementia	P, Q	Several including stroke and diabetes	82.2	Dementia 67.9, no dementia 55.8
Sakurai *et al.*, 2010[128]	Japan	Prevalence study	113 PLWD	Investigated prevalence of coexisting diseases in PLWD	P	Several including diabetes	78.6	73
Saposnik *et al.*, 2011[129]	Canada	Retrospective cohort	877 with pre-existing dementia, 877 control subjects (no pre-existing dementia)	Determine if pre-existing dementia is an independent predictor of all-cause mortality and disability after ischaemic stroke	P, Q	Stroke	82	60
Schubert *et al.*, 2006[2]	USA	Cross-sectional	Total: 3013 (107 PLWD)	Compare the medical comorbidity of older patients with and without dementia in primary care	P	Several including stroke and diabetes	73.4	66.6
Shah *et al.*, 2007[130]	UK	Survey	100 optometry practices	Investigate the accessibility of a sight test for an older person with dementia	Q	VI	NA	NA
Shamy and Jaigobin 2013[152]	Canada	Survey	NR but say they had a response rate of 69%	To better understand the decision-making process surrounding the administration of IV tPA	A	Stroke	Not known	Not known
Sinclair *et al.*, 2000[21]	UK	Case–control	396 with diabetes, 393 matched control subjects	Whether cognitive impairment is associated with changes in self-care behaviour and health service use in older diabetics	Q	Diabetes	Diabetics 74.9, control 74.8	51
Sinclair *et al.*, 2011[131]	Europe	Guidance	NA	Support clinical decisions in older people with diabetes and enhance high-quality diabetes care by the use of best available evidence	S	Diabetes	NA	NA

continued

TABLE 12 Details of studies included in the scoping review (*continued*)

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Sinclair *et al.*, 2014[147]	UK	Guidance	NA	Outline key steps in integrated care pathway for dementia and diabetes, produce guidance on identifying each condition, deal with potentially hazardous issue of hypoglycaemia and outline important competencies for HCPs in both settings	S	Diabetes	NA	NA
Sloan *et al.*, 2004[155]	USA	Cross-sectional (retrospective chart review)	5851 admitted for acute myocardial infarction with dementia, 123,241 admitted for AMI without dementia	Differences in mortality after admission for AMI and in treatments for AMI between patients with and without dementia	S	AMI	Dementia 81.6, no dementia 75.5	Dementia 57.2, no dementia 46.3
Spencer *et al.*, 2013[132]	UK	Qualitative	Total: 40 ($n = 20$ from specialist unit, $n = 20$ standard care)	Examine carers' views and experiences of delivery of patient care for PLWD in acute general hospital in order to evaluate specialist medical and mental health unit compared with standard hospital wards	V	General	NR	Not clear
Stenvall *et al.*, 2012[133]	Sweden	RCT	64 patients with fractured neck of femur ($n = 28$ intervention group, $n = 36$ control group)	Whether or not a multidisciplinary postoperative intervention programme reduced postoperative complications and improved functional recovery among people with dementia	S	Hip fracture	> 70	Intervention group 79, control group 69
Stephan *et al.*, 2011[134]	UK	Cross-sectional	Total: 13,004 ($n = 587$ PLWD, $n = 319$ MCI, $n = 608$ no cognitive impairment)	Compared the pattern of disease comorbidity across different cognitive groups and whether or not comorbidity is a risk factor for dementia progression	P	Several but includes diabetes and stroke	Dementia group – with health conditions 79.8, no health conditions 81.9	Dementia group – with health conditions 60.1, no health conditions 73.2

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Tadros *et al.*, 2013[135]	UK	Retrospective analysis	Not given	Evaluate whether or not implementation of the RAID integrated model improves access to psychiatric assessment and reduces costs of health service provision in an acute hospital	S	General	Mean age of referrals from all wards 65.7; 23% of RAID group and 20% of control group were aged > 75	RAID group 54, comparison group 40
Thorpe *et al.*, 2012[136]	USA	Retrospective cohort	Total: 288,805 ($n = 44,717$ PLWD)	Examined how recommended monitoring of diabetes differed for people with and without comorbid dementia	P, Q	Diabetes	26% aged 65–69, 48% aged 70–79, 25.9% aged 80+	60
Uhlmann *et al.*, 1989[138]	USA	Case–control	200 with hearing impairment ($n = 100$ with dementia, $n = 100$ control subjects)	Whether or not hearing impairment contributes to cognitive dysfunction in older adults	P	Hearing impairment	77	58
Uhlmann *et al.*, 1991[137]	USA	Case–control	87 PLWD, 87 matched control subjects	How impaired visual acuity is associated with dementia and cognitive dysfunction in older adults	P	VI	77	58
Vitry *et al.*, 2010[139]	Australia	Retrospective cohort	20,134 veterans with diabetes (includes people with dementia/cognitive impairment but numbers not clear)	Whether or not the number of comorbid conditions unrelated to diabetes delays therapeutic progression of diabetes treatment	Q	Diabetes	77.3	36
Whitson *et al.*, 2010[140]	USA	Cross-sectional	101 people with macular disease	Prevalence of comorbid cognitive impairment among older adults referred to low-vision rehabilitation for macular disease	P	VI (macular disease)	80.1	65

continued

TABLE 12 Details of studies included in the scoping review (*continued*)

Study ID	Country	Study design	Number of participants	Aims/research questions	Study focus[a]	Comorbidity	Age (years)[b]	Sex (% female)
Yochim *et al.*, 2012[141]	USA	Case series	41 glaucoma patients	Prevalence of cognitive impairment, depression and anxiety in older adults with glaucoma	P	VI	70	70
Zamrini *et al.*, 2004[142]	USA	Case–control	999 people with Alzheimer's disease	Prevalence of comorbid illness in black and white patients with probable Alzheimer's disease	P	Several but includes diabetes and eye disease	Female patients 75.1, male patients 73.1	49
Zekry *et al.*, 2008[143]	Switzerland	Cohort	349 inpatients (43.3% dementia, 10.6% MCI)	Comorbid conditions and functional and nutritional status in hospitalised patients with dementia and MCI	P	Several but includes data on stroke and diabetes	85	76
Zhang *et al.*, 2010[145]	Australia	Retrospective cohort	17,095 veterans with and without diabetes (4.4% on dementia medication)	Impact of comorbidity on health service utilisation by Australian veterans with diabetes	Q	Diabetes	81	44

AMI, acute myocardial infarction; IAT, intra-arterial reperfusion therapy; NA, not applicable; NR, not reported; RAID, Rapid Assessment, Interface and Discharge; SE, standard error.
a P, prevalence; Q, quality of care; S, service organisation and management; V, views and experiences.
b Unless otherwise stated refers to mean age and range.

TABLE 13 Prevalence studies: information on study populations, recruitment and participation

Study and country	Type of study	Type of population	Eligibility criteria defined?	Method of selection	Nature of population	Number of participants	Participation rate
Barnett *et al.*, 2012,[91] UK (Scotland)	Cross-sectional	General	Alive, permanently registered with a participating practice	National data set	Primary care (about one-third of all Scottish population)	11,139	All patients registered with primary care practice
Bruce *et al.*, 2003,[95] Australia	Longitudinal cross-sectional	Diabetes	Defined by postcode, age ≥ 70 years, diabetes	Initial 223 members of a cohort of 529 participants	Community-based volunteers who consented to take part	223	Initially recruited 63% of those who were eligible
Doraiswamy *et al.*, 2002,[1] USA	Cross-sectional	Dementia	Diagnosis of Alzheimer's disease, age ≥ 50 years	From a variety of community health-care sites	Volunteers who consented to take part	679	Not clear
Feil *et al.*, 2003,[101] USA	Longitudinal cross-sectional	Cognitive impairment	Geographically defined, age ≥ 65 years	Secondary data analysis of data set from community-based study	Community-based volunteers who consented to take part	7482 (1774 with cognitive impairment)	80% (baseline interview)
Feil *et al.*, 2009,[103] USA	Longitudinal cross-sectional	Diabetes	Diagnosis of type 2 diabetes, age ≥ 60 years	Electronic medical diagnosis of type 2 diabetes	Geriatric medical clinic	51	Not clear
Feil *et al.*, 2011,[104] USA	Cross-sectional	Diabetes	Veterans aged ≥ 65 with diabetes	Secondary data analysis of research administration database (Veterans Health Administration, Medicare and Medicaid)	Population-based sample – large national health-care system database	497,000	All patients on database
Heun *et al.*, 2013,[12] UK	Retrospective case–control	Dementia	Diagnosis of Alzheimer's disease, age 70+ years, inpatient care for at least 24 hours	Consecutively admitted inpatients	Hospital	634	All patients who met criteria were included
Hewitt *et al.*, 2010,[20] UK	Questionnaire	Diabetes (cognitive impairment)	Type 2 diabetes, age ≥ 75 years, not resident in a nursing home	Secondary data analysis of intervention arm of RCT	Primary care	1047	Not clear
Jara *et al.*, 2011,[144] UK	Retrospective cohort	Dementia	Age ≥ 64 years, at least 24 months' enrolment, no cataract diagnosis at baseline	National data set	Primary care	650,325 (8124 with dementia)	All patients registered with primary care practice

continued

TABLE 13 Prevalence studies: information on study populations, recruitment and participation (*continued*)

Study and country	Type of study	Type of population	Eligibility criteria defined?	Method of selection	Nature of population	Number of participants	Participation rate
Löppönen *et al.*, 2004,[118] Finland	Cross-sectional	Dementia	Geographically defined, age ≥ 65 years	All those who met criteria invited in random order	Population based	112	82%
Lyketsos *et al.*, 2005,[119] USA	Case–control	Dementia/ cognitive impairment	Geographically defined, age ≥ 65 years	All those who met criteria invited to participate	Population based	695 (374 with dementia)	90%
McCormick *et al.*, 1994,[121] USA	Case–control	Dementia/ cognitive impairment	Age ≥ 60 years, member of HMO, geographically defined	Subsample recruited from database (not clear how chosen)	From HMO database	154	Not clear
Pendlebury *et al.*, 2015[146]	Cross-sectional	Stroke	All patients with stroke or TIA	All those with stroke or TIA within defined population area. Recruited through general practice or secondary care	Population based	1236 (from a population of 92,728)	92%
Poblador-Plou *et al.*, 2014,[14] Spain	Cross-sectional	Dementia	Age ≥ 65 years, consulted physician at least once during the 12-month period of the study	Primary care data set (19 primary health-care centres)	Primary care	72,815 (3971 with dementia)	All patients who visit GP at least once during 2008
Rait *et al.*, 2010,[127] UK	Cohort	Dementia	Age 60+ years with first code for dementia during the study period, at least 6 months of data	National data set (practices that met standards for acceptable levels of data recording)	Primary care	135,174 (22,529 with dementia)	All patients registered with primary care practice
Sakurai *et al.*, 2010,[128] Japan	Cross-sectional	Dementia	Dementia or MCI	Consecutive outpatients attending memory clinic	Memory clinic	160	Not clear
Saposnik *et al.*, 2011,[129] Canada	Retrospective cohort	Stroke and dementia	Age ≥ 18 years, first ischaemic stroke	Stroke register	Clinical database	10,658	All stroke patients attending 12 regional stroke centres
Schubert *et al.*, 2006,[2] USA	Cross-sectional	Dementia	Age ≥ 65, seen primary care physician within 2 year. Excluded nursing home residents and non-English-speaking patients	Primary care practice centres	Primary care	3013 (107 dementia)	Not clear

Study and country	Type of study	Type of population	Eligibility criteria defined?	Method of selection	Nature of population	Number of participants	Participation rate
Stephan *et al.*, 2011,[134] UK	Cross-sectional	MCI	Age ≥ 65 years	Randomly selected from health authority lists in five areas of the UK	Population based	13,004 (1486 dementia)	Not clear
Uhlmann *et al.*, 1991,[137] USA	Case–control	Dementia	Age ≥ 65 years, English speaking, eighth grade of higher level of education, ability to complete audiometric evaluation	Computer searches of clinic records	Outpatient clinic	174 (87 dementia)	70%
Whitson *et al.*, 2010,[140] USA	Cross-sectional	VI (macular disease)	Age ≥ 65 years, macular disease diagnoses	All eligible patients attending clinic invited to participate	Outpatient clinic	101	74%
Yochim *et al.*, 2012,[141] USA	Case series	VI (glaucoma)	Age ≥ 50 years, diagnosis of glaucoma	All eligible patients attending clinic invited to participate	Outpatient clinic	41	Not reported
Zamrini *et al.*, 2004,[142] USA	Case–control	Dementia	Probable Alzheimer's disease, black or white (white participants matched non-randomly to black participants)	Computer searches of clinic records	Memory clinic	334	All those eligible during study period
Zekry *et al.*, 2008,[143] Switzerland	Cohort	Dementia	Age ≥ 75 years. Excluded those with a terminal illness or disorders interfering with psychometric assessment	Random sample of all patients admitted selected each day	Hospital inpatients	349 (188 dementia)	85%
Zhang *et al.*, 2010,[145] Australia	Retrospective cohort	Diabetes	Veterans, age ≥ 65, received prescription for diabetes in previous 6 months	Research administration database (Department of Veterans Affairs)	From database of veterans		All eligible patients on database

HMO, health maintenance organisation; TIA, transient ischaemic attack.

TABLE 14 Prevalence studies: information on methods for data collection

Study and country	Type of study	Type of population	Method of data collection	How dementia/cognitive impairment defined/assessed?	How diabetes defined/recorded?	How stroke defined/recorded?	How VI defined/recorded?	Other
Barnett *et al.*, 2012,[91] UK (Scotland)	Cross-sectional	General	Electronic medical records	Read code ever recorded	Read code ever recorded	Read code ever recorded	NA	
Bruce *et al.*, 2003,[95] Australia	Longitudinal cross-sectional	Diabetes	Face-to-face interview and clinical examination	MMSE (< 24/30), IQCODE (> 3.61), Cambridge Examination for Mental Disorders of the Elderly and diagnostic examination	Clinical and biochemical assessment			
Doraiswamy *et al.*, 2002,[1] USA	Cross-sectional	Dementia	Face-to-face interview and medical records	Diagnostic criteria for probable Alzheimer's disease (NINADS-ADRDA)	NA	NA	NA	Cumulative Illness Rating Scale–Geriatric
Feil *et al.*, 2003,[101] USA	Longitudinal cross-sectional	Cognitive impairment	Face-to-face interview	Modified version of Pfeiffer's Short Portable Mental Status Questionnaire (SPMSQ)	Self-reported	Self-reported	NA	
Feil *et al.*, 2009,[103] USA	Longitudinal cross-sectional	Diabetes	Face-to-face interview	Cognitive Abilities Screening Instrument (CASI)	Diagnosis confirmed by physician and patient	NA	NA	
Feil *et al.*, 2011,[104] USA	Cross-sectional	Diabetes	Medical records	ICD codes	Two or more diabetes-specific ICD codes (ICD-9-CM)	NA	NA	
Heun *et al.*, 2013,[12] UK	Retrospective case–control	Dementia	Retrospective data from clinical records	ICD-10 diagnostic category	Registered diagnosis in medical records	Registered diagnosis in medical notes	Registered diagnosis in medical notes	
Jara *et al.*, 2011,[144] UK	Retrospective cohort	Dementia	Electronic medical records	Not specified			Cataract-related surgical/diagnostic codes	

Study and country	Type of study	Type of population	Method of data collection	How dementia/cognitive impairment defined/assessed?	How diabetes defined/recorded?	How stroke defined/recorded?	How VI defined/recorded?	Other
Löppönen *et al.*, 2004,[118] Finland	Cross-sectional	Dementia	Face-to-face interview and clinical examination	Diagnostic criteria for probable Alzheimer's disease (NINADS-ADRDA), DSM-IV – clinical examination	Diagnosis in medical records and/or history of stroke verified by clinical examination	Diagnosis in medical records and/or treatment with antidiabetic agents and/or fasting plasma glucose level ≥ 7.0 mmol/l	NA	
Lyketsos *et al.*, 2005,[119] USA	Case–control	Dementia/ cognitive impairment	Face-to-face interview and clinical examination	Modified MMSE (3MS) or IQCODE plus clinical examination	Self- or informant response	Self- or informant response		
McCormick *et al.*, 1994,[121] USA	Case–control	Dementia/ cognitive impairment	Clinical examination and medical records	Diagnostic criteria for probable Alzheimer's disease (NINADS-ADRDA), DSM-III-R (clinical examination)	Diagnosis in medical records	Diagnosis in medical records	Diagnosis in medical records	Charleston Comorbidity Index
Poblador-Plou *et al.*, 2014,[14] Spain	Cross Sectional	Dementia	Electronic medical records	Expanded Diagnostic Clusters NUR11 category 'dementia and delirium'	Diagnosis in medical records (ICD codes)	Diagnosis in medical records (ICD codes)	medical records (ICD codes)	
Rait *et al.*, 2010,[127] UK	Cohort	Dementia	Electronic medical records	Read codes	Read codes	Read codes		
Sakurai *et al.*, 2010,[128] Japan	Cross-sectional	Dementia	Face-to-face interview and clinical examination	Diagnostic criteria for probable Alzheimer's disease (NINADS-ADRDA) – clinical examination	Receiving diabetes therapy or HbA_{1c} > 5.9% or diagnosis according to ADA guidelines	NA	NA	
Saposnik *et al.*, 2011,[129] Canada	Retrospective cohort	Stroke and dementia	Medical records and clinical examination	Any type of dementia recorded in notes	NA	Canadian Neurological Scale – clinical examination	NA	
Schubert *et al.*, 2006,[2] USA	Cross-sectional	Dementia	Medical records and clinical examination	ICD-10 – clinical examination	Coded ICD diagnosis	Coded ICD diagnosis	NA	Chronic Disease Score

continued

TABLE 14 Prevalence studies: information on methods for data collection (*continued*)

Study and country	Type of study	Type of population	Method of data collection	How dementia/cognitive impairment defined/assessed?	How diabetes defined/recorded?	How stroke defined/recorded?	How VI defined/recorded?	Other
Stephan *et al.*, 2011,[134] UK	Cross-sectional	MCI	Face-to-face interview	Mayo Clinic criteria for MCI	Self- or information response	Self- or information response		
Uhlmann *et al.*, 1991,[137] USA	Case–control	Dementia	Medical records	Diagnostic criteria for probable Alzheimer's disease (NINADS-ADRDA)	NA	NA	Snellen and Rosenbaum methods[249]	
Whitson *et al.*, 2010,[140] USA	Cross-sectional	VI (macular disease)	Clinical examination	Telephone Interview for Cognitive Status–Modified, Wechsler Memory Scale–Revised, letter fluency (FAS[a])	NA	NA	Diagnosis in medical records	
Yochim *et al.*, 2012,[141] USA	Case series	VI (glaucoma)	Data collection face to face or by telephone	California Verbal Learning Test Short Form, verbal fluency test (Delis–Kaplan Executive Function System)			Diagnosis in medical records	
Zamrini *et al.*, 2004,[142] USA	Case–control	Dementia	Medical records	Diagnostic criteria for probable Alzheimer's disease (NINADS-ADRDA)	Diagnosis in medical records	Diagnosis in medical records	Diagnosis in medical records	
Zekry *et al.*, 2008,[143] Switzerland	Cohort	Dementia	Clinical examination and medical records	MMSE and short cognitive evaluation; diagnosis based on clinical criteria (clinical examination)	Diagnosis in medical records	Diagnosis in medical records	Diagnosis in medical records	Charleston Comorbidity Index
Zhang *et al.*, 2010,[145] Australia	Retrospective cohort	Diabetes	Medical claims database	Database information on whether or not medication for dementia was dispensed	ICD codes			

ADA, American Diabetes Association; Revised; DSM-III-R, *Diagnostic and Statistical Manual of Mental Disorders*, 3rd Edition Revised HbA_{1c}, glycated haemoglobin; ICD, *International Classification of Diseases*; ICD-9-CM, *International Classification of Diseases*, 9th Revision, Clinical Modification; ICD-10, *International Classification of Diseases*, 10th Revision; IQCODE, Informant Questionnaire for Cognitive Decline in the Elderly; NA, not applicable; NINADS–ADRDA, National Institute of Neurological and Communicative Disorders and Stroke–Alzheimer's Disease and Related Disorders Association.

a Letters used in the letter fluency test (FAS).[250]

Appendix 5 Additional tables for the Cognitive Function and Ageing Studies analysis

Service questions used

Q554. Who usually helps (with day-to-day tasks)? CODE MAIN HELPER

A. No one.
B. Spouse.
C. Daughter.
D. Daughter-in-law.
E. Son.
F. Son-in-law.
G. Brother.
H. Sister.
I. Other relative.
J. Friend or neighbour.
K. Home help.
L. Care worker.
M. Meals on wheels.
N. Community worker.
O. Community nurse.
P. Warden.
Q. Paid help.
R. Other.
S. Not applicable.

IF A OR S SKIP TO Q559

Q556. Does anyone else help? CODE UP TO THREE OTHER HELPERS. First helper

A. No one.
B. Spouse.
C. Daughter.
D. Daughter-in-law.
E. Son.
F. Son-in-law.
G. Brother.
H. Sister.
I. Other relative.
J. Friend or neighbour.
K. Home help.
L. Care worker.
M. Meals on wheels.
N. Community worker.
O. Community nurse.
P. Warden.
Q. Paid help.
R. Other.
S. Not applicable.

Q557. Does anyone else help? Second helper

A. No one.
B. Spouse.
C. Daughter.
D. Daughter-in-law.
E. Son.
F. Son-in-law.
G. Brother.
H. Sister.
I. Other relative.
J. Friend or neighbour.
K. Home help.
L. Care worker.
M. Meals on wheels.
N. Community worker.
O. Community nurse.
P. Warden.
Q. Paid help.
R. Other.
S. Not applicable.

Q558. Does anyone else help? Third helper

A. No one.
B. Spouse.
C. Daughter.
D. Daughter-in-law.
E. Son.
F. Son-in-law.
G. Brother.
H. Sister.
I. Other relative.
J. Friend or neighbour.
K. Home help.
L. Care worker.
M. Meals on wheels.
N. Community worker.
O. Community nurse.
P. Warden.
Q. Paid help.
R. Other.
S. Not applicable.

Lastly, I'd like to ask you whether you have received various health or local authority services or any private help in recent weeks. So, in the *last 4 weeks*, have you seen or had a visit from or to any of the following services?

Q562. Local authority home help or home care assistant

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q563. Any nursing services

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q564. Chiropodist

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q565. Meals on wheels

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q566. Physiotherapist

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q567. Occupational therapist

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q568. Speech therapist

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q569. Social worker

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q570. Day centre

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q571. Day hospital

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q572. GP (the doctor)

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q573. During the last 3 complete calendar months, did you attend the casualty or outpatient department of a hospital (as a patient)?

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q574. Which month was this?

Month:

Q575. How many times did you attend the casualty or outpatient department during that month?

Q579. During the last year, have you been in hospital for treatment as a day patient (i.e. admitted to a hospital bed or day ward, but not required to stay overnight)?

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q580. How many separate days in hospital have you had as a day patient (in the last year)?

_____ Rate no of days

Q581. During the last year, have you been in hospital as an inpatient, overnight or longer?

0. No.
1. Yes.
8. No answer.
9. Not asked.

Q582. How many separate stays in hospital have you had as an inpatient (in the last year)?

_____ Rate no of days

Cognitive Function and Ageing Studies II-only analysis results (restricted to those living in the community)

Dementia and comorbidity compared with dementia

Stroke

Service use	IRR	95% CI
Any day-to-day service (count)	1.3	0.9 to 1.8
Any service in previous 4 weeks (count)	1.8	1.3 to 2.4
Outpatient in last 3 months (count)	1.2	0.6 to 2.2
Day patient in last year (count)	1.6	0.6 to 4.3
Inpatient in last year (count)	2.4	1.5 to 3.8
	OR	**95% CI**
Day-to-day services		
Home help	1.9	0.4 to 9.1
Care worker	3.1	1.4 to 6.6
Warden	1.2	0.1 to 12.0
Paid help	0.6	0.1 to 2.4
Any professional service	2.6	1.3 to 5.2
Unpaid care	1.7	0.8 to 3.6
Services in previous 4 weeks		
Home help/home care assistant	2.7	1.3 to 5.7
Any nursing services	1.9	0.9 to 4.1
Chiropodist	2.6	1.3 to 5.2
Physiotherapist	2.9	0.7 to 12.8
Occupational therapist	1.5	0.1 to 14.6
Social worker	3.2	0.7 to 15.3
Day centre	2.2	1.0 to 5.1
Day hospital	2.9	0.5 to 17.9
GP	1.5	0.8 to 2.9
Any service	2.0	0.9 to 4.1
Hospital services		
Casualty/outpatient	1.2	0.5 to 2.6
Day patient	1.2	0.5 to 3.0
Inpatient	4.4	2.2 to 8.9

IRR, incident rate ratio; OR, odds ratio.

Diabetes

Service use	IRR	95% CI
Any day-to-day service (count)	1.2	0.8 to 2.0
Any service in previous 4 weeks (count)	1.5	1.0 to 2.2
Outpatient in last 3 months (count)	2.1	1.1 to 3.9
Day patient in last year (count)	1.7	0.4 to 7.2
Inpatient in last year (count)	1.2	0.7 to 2.2
	OR	**95% CI**
Day-to-day services		
Home help	3.4	0.8 to 14.6
Care worker	0.8	0.3 to 2.2
Community nurse	8.4	1.1 to 65.4
Warden	1.2	0.1 to 12.6
Paid help	0.4	0.1 to 2.0
Any service	1.2	0.5 to 2.8
Unpaid care	1.4	0.6 to 3.0
Services in previous 4 weeks		
Home help	0.9	0.4 to 2.1
Any nursing service	3.5	1.7 to 7.5
Chiropodist	2.3	1.0 to 5.1
Meals on wheels	0.8	0.1 to 7.0
Physiotherapist	0.8	0.1 to 6.6
Occupation therapist	2.0	0.2 to 19.7
Social worker	2.0	0.3 to 13.6
Day centre	1.1	0.4 to 3.0
Day hospital	2.1	0.3 to 16.6
GP	1.1	0.6 to 2.2
Any service	1.7	0.7 to 3.8
Hospital services		
Casualty/outpatient	1.9	0.9 to 4.2
Day patient	0.6	0.2 to 1.8
Inpatient	2.0	0.9 to 4.3

IRR, incident rate ratio; OR, odds ratio.

Vision impairment

Service use	IRR	95% CI
Any day-to-day service (count)	1.1	0.7 to 1.5
Any service in previous 4 weeks (count)	1.2	0.9 to 1.5
Outpatient in last 3 months (count)	1.2	0.7 to 2.1
Day patient in last year (count)	1.4	0.6 to 3.6
Inpatient in last year (count)	1.7	0.9 to 3.1
	OR	**95% CI**
Day-to-day services		
Home help	0.4	0.0 to 3.2
Care worker	1.6	0.7 to 3.5
Community worker	1.0	0.1 to 11.7
Community nurse	4.1	0.6 to 30.0
Warden	0.9	0.1 to 8.6
Paid help	0.4	0.1 to 1.7
Any professional day-to-day service	1.7	0.8 to 3.6
Unpaid care	2.0	0.9 to 4.7
Services in previous 4 weeks		
Home help/home care assistant	1.4	0.6 to 3.1
Any nursing service	1.0	0.4 to 2.1
Chiropodist	2.1	1.0 to 4.3
Meals on wheels	0.6	0.1 to 5.1
Physiotherapist	0.7	0.1 to 5.5
Occupational therapist	1.6	0.2 to 15.9
Speech therapist	0.5	0.0 to 8.9
Social worker	0.3	0.0 to 2.9
Day centre	0.8	0.3 to 1.9
Day hospital	0.7	0.1 to 4.3
GP	1.5	0.8 to 3.0
Any service	6.1	1.7 to 21.4
Hospital services		
Casualty/outpatient	1.3	0.7 to 2.7
Day patient	1.4	0.6 to 3.6
Inpatient	1.9	0.9 to 4.0

IRR, incident rate ratio; OR, odds ratio.

Target comorbidities

Service use	IRR	95% CI
Any day-to-day service (count)	1.4	1.0 to 2.0
Any service in previous 4 weeks (count)	1.8	1.4 to 2.3
Outpatient in last 3 months (count)	1.7	1.0 to 2.8
Day patient in last year (count)	1.4	0.6 to 3.4
Inpatient in last year (count)	2.1	1.3 to 3.5
	OR	**95% CI**
Day-to-day services		
Home help	2.4	0.6 to 9.2
Care worker	2.1	1.1 to 4.2
Community worker	0.3	0.0 to 3.4
Warden	0.4	0.0 to 4.3
Paid help	0.6	0.2 to 1.7
Any professional day-to-day service	2.3	1.2 to 4.2
Unpaid care	2.3	1.3 to 4.1
Services in previous 4 weeks		
Home help/home care assistant	1.5	0.8 to 2.8
Any nursing service	2.8	1.5 to 5.2
Chiropodist	3.4	1.8 to 6.2
Meals on wheels	0.2	0.0 to 1.8
Physiotherapist	1.5	0.4 to 6.4
Social worker	1.3	0.3 to 6.0
Day centre	1.1	0.5 to 2.4
Day hospital	1.5	0.3 to 7.9
GP	1.5	0.9 to 2.5
Any service	3.4	1.9 to 6.2
Hospital services		
Casualty/outpatient	1.3	0.7 to 2.4
Day patient	0.8	0.4 to 1.9
Inpatient	3.2	1.7 to 5.9

IRR, incident rate ratio; OR, odds ratio.

Dementia and comorbidity compared with comorbidity alone

Dementia as well as stroke

Service use	IRR	95% CI
Any day-to-day service (count)	1.3	0.9 to 1.7
Any service in previous 4 weeks (count)	1.7	1.2 to 2.2
Outpatient in last 3 months (count)	0.6	0.4 to 1.1
Day patient in last year (count)	1.2	0.5 to 2.9
Inpatient in last year (count)	1.8	1.2 to 2.6
	OR	**95% CI**
Day-to-day services		
Home help	1.4	0.3 to 6.1
Care worker	9.2	4.3 to 19.5
Warden	0.8	0.1 to 7.1
Paid help	0.3	0.1 to 1.0
Any professional day-to-day service	2.8	1.5 to 5.3
Unpaid care	2.7	1.3 to 5.5
Services in the previous 4 weeks		
Home help/home care assistant	6.1	3.0 to 12.4
Any nursing service	2.0	1.0 to 4.2
Chiropodist	1.4	0.8 to 2.7
Physiotherapist	0.8	0.2 to 3.0
Occupational therapist	0.7	0.1 to 6.0
Day centre	6.8	3.1 to 14.9
Day hospital	4.9	1.0 to 24.6
GP	1.2	0.7 to 2.2
Any service	1.6	0.8 to 3.2
Hospital services		
Casualty/outpatient	0.8	0.3 to 1.6
Day patient	0.7	0.3 to 1.7
Inpatient	2.3	1.2 to 4.3

IRR, incident rate ratio; OR, odds ratio.

Dementia as well as diabetes

Service use	IRR	95% CI
Any day-to-day service (count)	1.3	0.8 to 2.1
Any service in previous 4 weeks (count)	1.5	1.1 to 2.2
Outpatient in last 3 months (count)	1.1	0.6 to 2.1
Day patient in last year (count)	1.3	0.3 to 5.3
Inpatient in last year (count)	1.4	0.8 to 2.3
	OR	**95% CI**
Day-to-day services		
Home help	2.4	0.6 to 9.1
Care worker	6.5	2.3 to 18.2
Warden	0.8	0.1 to 6.3
Paid help	0.2	0.0 to 1.0
Other	3.3	0.6 to 18.3
Any professional day-to-day service	1.9	0.9 to 4.0
Unpaid care	3.6	1.8 to 7.5
Services in previous 4 weeks		
Home help/home care assistant	4.1	1.8 to 9.6
Any nursing service	2.9	1.5 to 5.8
Chiropodist	1.0	0.5 to 2.1
Meals on wheels	0.6	0.1 to 5.3
Physiotherapist	0.6	0.1 to 4.6
Occupational therapist	1.9	0.2 to 15.4
Day centre	7.8	2.8 to 21.8
Day hospital	4.4	0.7 to 28.0
GP	1.0	0.5 to 1.9
Any service	1.5	0.7 to 3.2
Hospital services		
Casualty/outpatient	1.3	0.6 to 2.7
Day patient	0.4	0.1 to 1.2
Inpatient	1.6	0.8 to 3.3

IRR, incident rate ratio; OR, odds ratio.

Dementia as well as vision impairment

Service use	IRR	95% CI
Any day-to-day service (count)	1.3	0.9 to 1.8
Any service in previous 4 weeks (count)	1.5	1.2 to 1.8
Outpatient in last 3 months (count)	0.7	0.5 to 1.1
Day patient in last year (count)	1.2	0.5 to 2.7
Inpatient in last year (count)	2.2	1.3 to 3.9
	OR	**95% CI**
Day-to-day services		
Home help	0.4	0.1 to 3.7
Care worker	9.1	4.3 to 19.5
Warden	0.9	0.1 to 6.8
Paid help	0.2	0.1 to 0.9
Any professional day-to-day service	2.6	1.2 to 5.3
Unpaid care	4.8	2.1 to 10.8
Services in previous 4 weeks		
Home help/home care assistant	5.3	2.5 to 11.4
Any nursing service	1.2	0.6 to 2.6
Chiropodist	1.8	1.0 to 3.4
Meals on wheels	0.6	0.1 to 5.2
Physiotherapist	0.3	0.0 to 2.3
Occupational therapist	1.0	0.1 to 8.1
Day centre	7.4	2.8 to 19.7
Day hospital	2.0	0.4 to 9.2
GP	1.6	0.8 to 3.0
Any service	7.7	2.2 to 26.5
Hospital services		
Casualty/outpatient	0.9	0.5 to 1.8
Day patient	1.0	0.4 to 2.3
Inpatient	2.2	1.1 to 4.2

IRR, incident rate ratio; OR, odds ratio.

Dementia as well as any one of the target comorbidities

Service use	IRR	95% CI
Any day-to-day service (count)	1.4	1.0 to 1.8
Any service in previous 4 weeks (count)	1.6	1.3 to 2.0
Outpatient in last 3 months (count)	0.8	0.5 to 1.2
Day patient in last year (count)	1.1	0.5 to 2.2
Inpatient in last year (count)	1.8	1.3 to 2.6
	OR	**95% CI**
Day-to-day services		
Home help	1.5	0.5 to 4.0
Care worker	8.0	4.6 to 14.0
Warden	0.4	0.1 to 3.2
Paid help	0.3	0.1 to 0.8
Other day-to-day services	1.9	0.4 to 9.9
Any service	2.3	1.5 to 3.8
Unpaid services	4.1	2.5 to 6.6
Services in previous 4 weeks		
Home help/home care assistant	5.2	3.1 to 8.7
Any nursing services	2.2	1.4 to 3.5
Chiropodist	1.5	1.0 to 2.4
Meals on wheels	0.3	0.0 to 2.6
Physiotherapist	0.6	0.2 to 1.8
Occupational therapist	1.8	0.5 to 6.2
Day centre	7.2	3.8 to 13.6
Day hospital	3.4	1.0 to 10.9
GP	1.3	0.9 to 2.0
Any service	2.3	1.4 to 3.8
Hospital services		
Casualty/outpatient	0.9	0.6 to 1.4
Day patient	0.6	0.3 to 1.2
Inpatient	1.9	1.2 to 3.0

IRR, incident rate ratio; OR, odds ratio.

Comparison analysis results (restricted to those aged ≥ 75 years and living in the community)

Dementia and comorbidity compared with dementia

Stroke

	CFAS I		CFAS II	
Service use	**IRR**	**95% CI**	**IRR**	**95% CI**
Any day-to-day service (count)	3.2	1.9 to 5.3	1.5	1.0 to 2.4
Any service in previous 4 weeks (count)	1.5	1.0 to 2.4	2.0	1.3 to 3.0
Outpatient in last 3 months (count)	1.0	0.2 to 4.2	0.9	0.3 to 2.2
Day patient in last year (count)	–	–	2.2	0.7 to 6.6
Inpatient in last year (count)	3.9	1.2 to 12.2	3.3	1.8 to 5.9
	OR	**95% CI**	**OR**	**95% CI**
Day-to-day services				
Home help	1.8	0.3 to 11.4	1.8	0.3 to 11.3
Care worker	4.7	1.4 to 15.2	3.8	1.5 to 9.6
Warden	–	–	1.2	0.1 to 12.7
Paid help	–	–	0.8	0.2 to 3.6
Any professional service	7.6	2.1 to 27.7	2.7	1.2 to 6.0
Unpaid care	3.3	1.0 to 10.9	1.9	0.8 to 4.3
Services in previous 4 weeks				
Home help/home care assistant	3.7	1.1 to 12.5	2.4	1.0 to 5.8
Any nursing services	0.9	0.2 to 3.6	2.4	1.0 to 6.0
Chiropodist	0.6	0.1 to 3.1	3.3	1.5 to 7.1
Meals on wheels	6.6	1.6 to 26.7	–	–
Day centre	–	–	4.0	1.5 to 10.5
GP	0.7	0.2 to 2.9	1.6	0.7 to 3.5
Any service	1.3	0.4 to 4.3	0.9	0.7 to 3.3
Hospital services				
Casualty/outpatient	1.4	0.3 to 7.3	0.9	0.3 to 2.8
Day patient	–	–	1.7	0.6 to 5.0
Inpatient	5.6	1.4 to 22.8	5.9	2.6 to 13.9

IRR, incident rate ratio; OR, odds ratio.

Diabetes

	CFAS I		CFAS II	
Service use	**IRR**	**95% CI**	**IRR**	**95% CI**
Any day-to-day service (count)	1.1	0.5 to 2.1	1.3	0.8 to 2.2
Any service in previous 4 weeks (count)	1.5	0.8 to 2.5	1.8	1.1 to 2.9
Outpatient in last 3 months (count)	1.1	0.3 to 3.9	1.3	0.6 to 2.8
Day patient in last year (count)	–	–	1.7	0.4 to 7.9
Inpatient in last year (count)	1.2	0.3 to 4.0	1.1	0.6 to 2.2
	OR	**95% CI**	**OR**	**95% CI**
Day-to-day services				
Home help	–	–	3.7	0.7 to 19.7
Care worker	0.9	0.2 to 3.7	1.0	0.3 to 2.7
Warden	–	–	1.3	0.1 to 13.1
Paid help	–	–	0.3	0.0 to 2.1
Any service	1.6	0.4 to 5.8	1.5	0.7 to 3.5
Unpaid care	1.7	0.5 to 6.0	1.7	0.8 to 3.8
Services in previous 4 weeks				
Home help	0.7	0.1 to 2.9	1.0	0.4 to 2.5
Any nursing service	3.7	1.0 to 14.2	3.6	1.5 to 8.6
Chiropodist	0.9	0.2 to 4.0	1.8	0.8 to 4.1
Meals on wheels	1.1	0.2 to 5.2	0.8	0.1 to 7.2
Day centre	3.8	0.7 to 20.9	1.6	0.5 to 5.0
Day hospital	–	–	–	–
GP	1.6	0.4 to 5.6	1.1	0.5 to 2.3
Any service	1.9	0.4 to 8.2	1.9	0.8 to 4.4
Hospital services				
Casualty/outpatient	0.8	0.2 to 3.8	1.5	0.6 to 4.0
Day patient	–	–	0.6	0.2 to 2.3
Inpatient	1.4	0.3 to 5.6	2.0	0.8 to 5.1

IRR, incident rate ratio; OR, odds ratio.

Vision impairment

	CFAS I		CFAS II	
Service use	**IRR**	**95% CI**	**IRR**	**95% CI**
Any day-to-day service (count)	1.4	0.7 to 2.5	1.1	0.7 to 1.7
Any service in previous 4 weeks (count)	1.0	0.6 to 1.7	1.2	0.8 to 1.6
Outpatient in last 3 months (count)	1.5	0.4 to 5.4	1.2	0.6 to 2.4
Day patient in last year (count)	–	–	1.2	0.4 to 3.8
Inpatient in last year (count)	3.1	0.9 to 11.3	1.9	0.9 to 3.9
	OR	**95% CI**	**OR**	**95% CI**
Day-to-day services				
Home help	0.8	0.1 to 7.7	0.5	0.1 to 4.9
Care worker	3.4	1.0 to 12.3	1.5	0.6 to 3.9
Warden	–	–	0.9	0.1 to 8.7
Paid help	0.4	0.0 to 4.7	0.2	0.0 to 1.5
Any professional day-to-day service	1.6	0.5 to 5.0	1.5	0.6 to 3.6
Unpaid care	1.6	0.5 to 5.0	2.1	0.9 to 4.9
Services in previous 4 weeks				
Home help/home care assistant	2.8	0.8 to 10.5	1.0	0.4 to 2.6
Any nursing service	0.6	0.1 to 2.7	1.0	0.4 to 2.5
Chiropodist	0.6	0.1 to 3.1	2.1	1.0 to 4.7
Meals on wheels	4.1	1.0 to 17.4	0.6	0.1 to 5.9
Day centre	–	–	0.8	0.3 to 2.6
Day hospital	–	–	–	–
GP	0.4	0.1 to 1.7	1.1	0.5 to 2.5
Any service	0.6	0.2 to 1.9	3.3	1.2 to 8.7
Hospital services				
Casualty/outpatient	2.9	0.6 to 14.0	1.0	0.4 to 2.5
Day patient	–	–	1.3	0.4 to 3.9
Inpatient	3.4	0.7 to 16.1	1.9	0.8 to 4.7

IRR, incident rate ratio; OR, odds ratio.

Target comorbidities

	CFAS I		CFAS II	
Service counts	**IRR**	**95% CI**	**IRR**	**95% CI**
Any day-to-day service (count)	2.0	1.1 to 3.6	1.5	1.0 to 2.4
Any service in previous 4 weeks (count)	1.4	0.9 to 2.1	2.1	1.5 to 2.9
Outpatient in last 3 months (count)	0.8	0.3 to 2.5	1.1	0.6 to 2.0
Day patient in last year (count)	0.9	0.1 to 12.9	1.6	0.5 to 4.9
Inpatient in last year (count)	4.6	1.2 to 18.3	2.3	1.2 to 4.4
	OR	**95% CI**	**OR**	**95% CI**
Day-to-day services				
Home help	0.6	0.1 to 3.3	3.6	0.6 to 20.2
Care worker	2.9	0.9 to 9.1	2.2	1.0 to 4.8
Warden	–	–	0.5	0.0 to 4.6
Paid help	–	–	0.6	0.2 to 1.8
Any professional day-to-day service	2.4	0.9 to 6.7	2.3	1.2 to 4.6
Unpaid care	1.8	0.7 to 4.8	2.5	1.3 to 4.7
Services in previous 4 weeks				
Home help/home care assistant	1.6	0.5 to 4.9	1.2	0.6 to 2.6
Any nursing service	2.6	0.8 to 8.9	3.1	1.5 to 6.6
Chiropodist	0.8	0.3 to 2.5	3.3	1.7 to 6.6
Meals on wheels	–	–	0.2	0.0 to 2.1
Day centre	3.5	0.6 to 21.8	1.7	0.7 to 4.3
Day hospital	–	–	–	–
GP	1.1	0.4 to 3.1	1.4	0.8 to 2.6
Any service	0.9	0.3 to 2.3	2.8	1.6 to 5.1
Hospital services				
Casualty/outpatient	1.5	0.4 to 5.4	0.8	0.4 to 1.8
Day patient	0.8	0.0 to 13.9	0.9	0.3 to 2.3
Inpatient	7.1	1.8 to 27.4	3.1	1.5 to 6.6

IRR, incident rate ratio; OR, odds ratio.

Dementia and comorbidity compared with comorbidity alone

Dementia as well as stroke

	CFAS I		CFAS II	
Service counts	**IRR**	**95% CI**	**IRR**	**95% CI**
Any day-to-day service (count)	2.0	1.3 to 3.1	1.2	0.8 to 1.9
Any service in previous 4 weeks (count)	1.1	0.7 to 1.6	1.6	1.1 to 2.3
Outpatient in last 3 months (count)	0.6	0.1 to 2.4	0.4	0.2 to 1.0
Day patient in last year (count)	–	–	1.4	0.6 to 3.4
Inpatient in last year (count)	3.5	1.4 to 9.0	1.9	1.2 to 3.1
	OR	**95% CI**	**OR**	**95% CI**
Day-to-day services				
Home help	2.8	0.4 to 18.0	1.1	0.2 to 6.0
Care worker	5.5	1.9 to 16.1	9.3	3.8 to 22.5
Warden	–	–	1.0	0.1 to 9.0
Paid help	1.4	0.3 to 7.5	0.3	0.1 to 1.2
Any professional day-to-day service	4.1	1.2 to 13.7	2.1	1.0 to 4.3
Unpaid care	1.2	0.4 to 3.6	1.9	0.9 to 4.3
Services in the previous 4 weeks				
Home help/home care assistant	4.1	1.3 to 12.7	5.8	2.5 to 13.6
Any nursing service	0.7	0.2 to 2.6	2.2	0.9 to 5.2
Chiropodist	0.4	0.1 to 1.8	2.1	1.0 to 4.2
Day centre	2.4	0.5 to 11.2	10.0	4.0 to 25.1
GP	0.6	0.2 to 2.2	1.1	0.5 to 2.4
Any service	0.6	0.2 to 1.8	0.8	0.4 to 1.7
Hospital services				
Casualty/outpatient	0.9	0.2 to 4.5	0.6	0.2 to 1.8
Day patient	–	–	0.9	0.4 to 2.4
Inpatient	4.9	1.4 to 17.7	2.5	1.2 to 5.4

IRR, incident rate ratio; OR, odds ratio.

Dementia as well as diabetes

	CFAS I		CFAS II	
Service counts	**IRR**	**95% CI**	**IRR**	**95% CI**
Any day-to-day service (count)	1.2	0.6 to 2.2	1.1	0.7 to 1.8
Any service in previous 4 weeks (count)	1.0	0.6 to 1.7	1.4	0.9 to 2.2
Outpatient in last 3 months (count)	0.5	0.2 to 1.4	0.6	0.3 to 1.2
Day patient in last year (count)	0.4	0.1 to 2.7	1.0	0.2 to 4.3
Inpatient in last year (count)	1.3	0.5 to 3.6	0.9	0.5 to 1.6
	OR	**95% CI**	**OR**	**95% CI**
Day-to-day services				
Home help	–	–	2.1	0.5 to 9.7
Care worker	1.8	0.5 to 6.8	5.0	1.8 to 14.1
Warden	–	–	0.8	0.1 to 7.1
Paid help	0.8	0.1 to 7.0	0.1	0.0 to 0.8
Other	–	–	1.1	0.1 to 9.6
Any professional day-to-day service	1.9	0.5 to 6.3	1.4	0.7 to 3.1
Unpaid care	0.9	0.3 to 2.8	2.8	1.3 to 5.9
Services in previous 4 weeks				
Home help/home care assistant	1.3	0.3 to 5.6	3.7	1.4 to 9.4
Any nursing service	1.3	0.4 to 4.4	2.4	1.1 to 5.4
Chiropodist	0.4	0.1 to 1.5	0.9	0.4 to 2.0
Meals on wheels	1.6	0.4 to 6.8	0.6	0.1 to 5.7
Day centre	2.8	0.6 to 12.6	6.8	2.2 to 21.0
GP	1.0	0.3 to 3.4	0.9	0.4 to 1.8
Any service	0.6	0.1 to 2.4	1.0	0.5 to 2.2
Hospital services				
Casualty/outpatient	0.3	0.1 to 1.4	0.9	0.4 to 2.4
Day patient	0.5	0.1 to 4.1	0.4	0.1 to 1.4
Inpatient	1.4	0.4 to 4.8	1.3	0.5 to 3.0

IRR, incident rate ratio; OR, odds ratio.

Dementia as well as vision impairment

	CFAS I		CFAS II	
Service counts	**IRR**	**95% CI**	**IRR**	**95% CI**
Any day-to-day service (count)	1.5	0.9to 2.6	1.1	0.7 to 1.7
Any service in previous 4 weeks (count)	0.9	0.6 to 1.6	1.3	1.0 to 1.6
Outpatient in last 3 months (count)	0.9	0.3 to 3.0	0.6	0.3 to 1.1
Day patient in last year (count)	0.4	0.1 to 2.7	0.8	0.3 to 2.1
Inpatient in last year (count)	3.5	1.1 to 11.5	1.7	0.9 to 3.2
	OR	**95% CI**	**OR**	**95% CI**
Day-to-day services				
Home help	2.1	0.2 to 19.3	0.5	0.1 to 4.4
Care worker	5.8	1.8 to 19.2	6.4	2.6 to 15.5
Warden	–	–	0.9	0.1 to 7.8
Paid help	0.2	0.0 to 1.9	0.1	0.0 to 0.7
Any professional day-to-day service	2.0	0.7 to 5.9	1.6	0.7 to 3.7
Unpaid care	0.9	0.3 to 2.5	2.9	1.3 to 6.7
Services in previous 4 weeks				
Home help/home care assistant	4.4	1.3 to 15.0	3.4	1.3 to 8.5
Any nursing service	0.5	0.1 to 1.9	1.0	0.4 to 2.4
Chiropodist	0.5	0.1 to 2.5	1.8	0.9 to 3.8
Meals on wheels	–	–	0.8	0.1 to 6.6
Day centre	–	–	6.5	2.0 to 20.7
GP	0.4	0.1 to 1.6	1.1	0.5 to 2.2
Any service	0.4	0.1 to 1.1	2.9	1.1 to 7.5
Hospital services				
Casualty/outpatient	1.9	0.4 to 8.5	0.7	0.3 to 1.5
Day patient	0.5	0.1 to 4.5	0.8	0.3 to 2.3
Inpatient	3.4	0.8 to 14.7	1.5	0.7 to 3.4

IRR, incident rate ratio; OR, odds ratio.

Dementia as well as any one of the target comorbidities

	CFAS I		CFAS II	
Service counts	**IRR**	**95% CI**	**IRR**	**95% CI**
Any day-to-day service (count)	1.6	1.1 to 2.4	1.1	0.8 to 1.6
Any service in previous 4 weeks (count)	1.1	0.8 to 1.5	1.4	1.1 to 1.8
Outpatient in last 3 months (count)	0.5	0.2 to 1.2	0.5	0.3 to 0.8
Day patient in last year (count)	0.1	0.0 to 1.0	0.9	0.4 to 2.1
Inpatient in last year (count)	2.6	1.3 to 5.5	1.4	0.9 to 2.2
	OR	**95% CI**	**OR**	**95% CI**
Day-to-day services				
Home help	1.6	0.3 to 8.1	1.5	0.5 to 4.4
Care worker	4.2	1.9 to 9.0	5.6	3.0 to 10.4
Warden	–	–	0.5	0.1 to 3.8
Paid help	0.8	0.2 to 2.6	0.2	0.1 to 0.6
Other day-to-day services	–	–	0.7	0.1 to 5.7
Any service	2.0	1.0 to 4.3	1.5	0.9 to 2.6
Unpaid services	0.8	0.4 to 1.6	2.7	1.6 to 4.5
Services in previous 4 weeks				
Home help/home care assistant	2.9	1.2 to 6.7	4.1	2.3 to 7.6
Any nursing services	1.2	0.5 to 2.6	2.0	1.1 to 3.5
Chiropodist	0.5	0.2 to 1.4	1.6	1.0 to 2.7
Meals on wheels	5.3	2.2 to 12.8	0.4	0.0 to 3.2
Physiotherapist	4.5	0.6 to 36.0	0.6	0.2 to 2.1
Occupational therapist	–	–	2.3	0.6 to 8.6
Day centre	1.8	0.6 to 5.5	7.2	3.4 to 15.1
GP	0.9	0.4 to 1.9	1.1	0.7 to 1.7
Any service	0.5	0.2 to 1.0	1.2	0.8 to 2.0
Hospital services				
Casualty/outpatient	0.8	0.3 to 2.1	0.6	0.3 to 1.1
Day patient	0.2	0.0 to 1.3	0.6	0.3 to 1.2
Inpatient	3.1	1.3 to 7.1	1.5	0.9 to 2.6

IRR, incident rate ratio; OR, odds ratio.

EME
HS&DR
HTA
PGfAR
PHR

Part of the NIHR Journals Library
www.journalslibrary.nihr.ac.uk

Published by the NIHR Journals Library